

**APPENDIX D: SUMMARY GRID
OF ISSUES, RECOMMENDATIONS OF
PANELISTS, AND FEDERAL RESPONSE**

CHALLENGE For Children With Co-Occurring Developmental Disabilities And Emotional/Substance Abuse Disorders	RECOMMENDATIONS OF PANELISTS	FEDERAL SOLUTIONS
MAKING SERVICES MORE ACCESSIBLE AND CHILD AND FAMILY CENTERED		OD: <ul style="list-style-type: none"> • Coordinate interdepartmental supporting actions.
<ul style="list-style-type: none"> • Change current fragmented service delivery by developing strong leadership and infrastructures to convert a silo approach to systems of care across all states. 	<ul style="list-style-type: none"> • Provide technical assistance (TA) to states to develop governance structures that support the systems of care approach. • Provide multiple access points for services to ensure a “no wrong door” approach. • Offer federal incentive grants to state health and human services authorities (e.g., education, mental health, developmental disabilities, substance abuse, primary care, child welfare, juvenile justice, Medicaid, transportation, housing) to plan integrated systems of care. This requires increased interdepartmental collaboration and coordination. • Insist on state/county interagency collaboration and inclusion of this 	ACF: <ul style="list-style-type: none"> • Include the systems of care needs of children with co-occurring disorders in the Family Support 360 grants. • Use the array of ADD networks to highlight the comprehensive needs of this population and develop supporting leadership. CMS: <ul style="list-style-type: none"> • Assess how the current Systems Change grants and other Medicaid opportunities can help address systems integration challenges for which Medicaid has jurisdiction. • Explore how co-occurring disorders can be incorporated into the Medicaid Disability Division’s strategic action plan.

	<p>population when awarding departmental/agency grants, waivers, or cooperative agreements.</p> <ul style="list-style-type: none"> • Promote the use of a single plan of care for each child based on need, not diagnosis, and regardless of funding. • Increase access for families to non-clinical supports such as in-home help, respite care, after school services, family support and advocacy. 	<p>HRSA/MCHB:</p> <ul style="list-style-type: none"> • Use the Federal Interagency Coordinating Council and the Medical Home Initiative to help address the comprehensive approach and leadership needed to support this population. <p>SAMHSA:</p> <ul style="list-style-type: none"> • Continue to address as part of mental health transformation, including obtaining support from the Senior Federal Workgroup • Include attention to this target group in state infrastructure and systems of care grants, and ongoing TA efforts. <p>DED:</p> <ul style="list-style-type: none"> • Identify how current and future OSEP grants support systems infrastructure and leadership development. • Identify how the IDEA can support systems infrastructure and leadership development. <p>FTA:</p> <ul style="list-style-type: none"> • Include this population in the continuing development of the nationwide human service
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		<p>transportation in continued work with federal departments on transportation one-stop information systems.</p> <p>HUD:</p> <ul style="list-style-type: none"> • Identify how current public housing supports for families can help address this population’s housing needs. <p>DOJ:</p> <ul style="list-style-type: none"> • Identify how current interdepartmental funding (e.g., with SAMHSA) can include this population. • Identify how all current and planned grants can include this population. <p>DOL:</p> <ul style="list-style-type: none"> • Address the needs of older youth who have fallen through the cracks and who may have co-occurring disorders to learn effective ways to help this group navigate through child welfare, juvenile justice, school and the labor force. • Identify how DOL’s “no wrong door” programs can address this population. <p>SSA:</p> <ul style="list-style-type: none"> • Assess use of infrastructure grants
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		<p>addressing youth in transition and other demonstration funding to support this population.</p> <p>ALL DEPARTMENTS:</p> <ul style="list-style-type: none"> • Examine the various federal interagency efforts to develop state/community leadership and foster infrastructure development.
<ul style="list-style-type: none"> • Family members are not consistently included or involved in decision making at all levels of government, training and service planning. 	<ul style="list-style-type: none"> • Increase access for families to non-clinical supports such as in-home help, respite care, after school services, family support and advocacy. • Include family concerns through the ACF/ADD Family Support 360 grants. • Never should a family be forced to relinquish custody of a child in order to access the services the child needs. • Increase access for families to non-clinical supports such as in-home help, respite care, after school services, family support and advocacy. • Involve families in all discussions, service plan development and treatment so that the family can help drive the decision making. 	<p>HRSA/MCHB:</p> <ul style="list-style-type: none"> • Assess through the Federal Interagency Coordinating Council and the Medical Home Initiative how families of children with these co-occurring disorders are included in all aspects of planning at the federal, state, community, and provider levels and implement an action plan to enhance such involvement. <p>SAMHSA:</p> <ul style="list-style-type: none"> • Continue to address as part of the mental health transformation. <p>DOJ:</p> <ul style="list-style-type: none"> • Assess current initiatives and federal partnerships on how families are included and implement an action plan to enhance such involvement.

		SSA, CMS, SAMHSA: <ul style="list-style-type: none"> • Assess how more emphasis on providing families with purchasing power can enhance individual and family self-determination.
<ul style="list-style-type: none"> • Screening and early detection of co-occurring disorders are not consistently used on entry into child services. • Restrictive and inconsistent eligibility criteria and limited access to services remain a challenge in meeting this population's needs. • Maintaining continuity of care is problematic as children transition between early childhood to school age and between adolescence to adulthood. 	<ul style="list-style-type: none"> • Provide more early intervention services to identify children with co-occurring disorders and assure screening on entry into any state/county system. • Train providers to recognize symptoms both at intake/referral and for children already receiving services. • Provide training and technical assistance activities in order to identify and ensure utilization of evidence based screening tools which include attention to securing parental consent, and service linkages. • Develop an appropriate single plan of care for these children based on need, not diagnoses, regardless of funding. • Families should not be forced to relinquish custody of a child in order to access services. 	ACF: <ul style="list-style-type: none"> • Use the array of service and system networks to highlight and address screening, service access and continuity of care for this population. • Use the ADD networks to train providers in systems of care for this population including the importance of “no wrong door” service approach. CMS: <ul style="list-style-type: none"> • Investigate concerns that waivers negatively affect access and eligibility by being too categorical for this population. HRSA/MCHB: <ul style="list-style-type: none"> • Use MCHB Federal Interagency Coordinating Council and the Medical Home Initiative to address eligibility and screening barriers.

	<ul style="list-style-type: none"> • Provide a single location within the community where assessment and comprehensive wrap-around planning can occur. • Address transitions between the early childhood/early intervention systems and the school age systems. • Address transitions between the child and adult systems. 	<p>SAMHSA:</p> <ul style="list-style-type: none"> • Use the Mental Health Transformation Federal National Partnership to help address the eligibility and screening barriers of this population. • Utilize available training and technical assistance programs to develop infrastructure supports and enhance providers' skills on screening and eligibility for this population. • Collaborate with the Centers for Disease Control (CDC) on screening for this population. • Explore collaboration with the Department of Defense (DOD) to facilitate coordination of services for deployed and redeployed military families. <p>DED:</p> <ul style="list-style-type: none"> • Assess how the IDEA and other initiatives/programs can help address the screening and eligibility needs of this population. <p>DOL:</p> <ul style="list-style-type: none"> • Address how ODEP and other DOL offices are addressing the screening, eligibility, employment and transition
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		<p>needs of older youth with these disorders.</p> <p>SSA:</p> <ul style="list-style-type: none"> • Investigate how SSI might relieve screening and eligibility constraints imposed by Medicaid. • Try to help the Office on Management and Budget (OMB) understand that it is economically wise to invest in screening, early detection and early intervention. • Seek guidance from other federal departments regarding data on cost benefit and specific recommendations for OMB.
<ul style="list-style-type: none"> • Too many children with co-occurring disorders are placed in the child welfare or juvenile justice system where their needs are not understood and addressed, often due to lack of community services. 	<ul style="list-style-type: none"> • Provide adequate community-based resources to prevent unnecessary criminalization and/or foster care placement. • Address, through leadership and attention to administrative infrastructure development, current categorical funding and silo service delivery systems. • Educate the juvenile justice and child welfare officials on identification of and community-based alternatives. 	<p>ACF:</p> <ul style="list-style-type: none"> • Use existing programs and initiatives to help address both avoidable child welfare placements and mechanisms to improve access to needed services for this target population. • Identify how the IV-E waivers in the Children's Bureau can be used to target this population to prevent unnecessary child welfare placements/parental relinquishment.

		<p>CMS:</p> <ul style="list-style-type: none"> • Investigate the concern that waivers are too categorical and are not offering the flexibility to fully address the complex needs of children with this class of disorders. • Identify how co-occurring disorders can be incorporated into the Medicaid Disability Division's Strategic Action Plan. <p>SAMHSA and DOJ:</p> <ul style="list-style-type: none"> • Identify how current and planned interdepartmental initiatives are or can address unnecessary out of home placements. <p>SSA:</p> <ul style="list-style-type: none"> • Investigate further how SSI might be used to help prevent unnecessary out of home placements by addressing Medicaid constraints. <p>ALL DEPARTMENTS:</p> <ul style="list-style-type: none"> • Assess current state plans as to preventing unnecessary child relinquishment.
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INCREASING CAPACITY IN THE FIELD		OD: <ul style="list-style-type: none"> • Coordinate interdepartmental supporting actions.
<ul style="list-style-type: none"> • Inadequate professional training on screening, assessing, treating and structuring services for children with co-occurring disorders. 	<ul style="list-style-type: none"> • Increase understanding and awareness of the needs of children with co-occurring disorders among primary care providers. • Increase understanding and awareness of the needs of children with co-occurring disorders among child care providers and educators. • Integrate developmental disabilities and mental health services within the schools and the primary care environment. • Recruit child psychiatrists and psychologists and other professionals to work with young people who have co-occurring disorders including autism. • Help higher education state systems develop multi-disciplinary training programs for staff working with this population. • Develop scholarships and education loan forgiveness to encourage professional cross-training. • Promote development of federal, state and county interdepartmental cross-training programs. 	ACF: <ul style="list-style-type: none"> • Use the training capacity of the ADD networks to specifically target TA and training related to this population. HRSA/MCHB: <ul style="list-style-type: none"> • Continue to develop the Medical Home Initiative that is working with pediatricians to engage in early identification of behavioral health and developmental needs. SAMHSA: <ul style="list-style-type: none"> • Continue and enhance training and technical assistance activities to influence practices in screening, treating, and structuring services. ALL DEPARTMENTS: <ul style="list-style-type: none"> • Assess current and planned training and TA on screening, treatment and service structures.

<p>FACILITATING INTERAGENCY COLLABORATION AND PARTNERSHIP AT THE LOCAL, STATE AND FEDERAL LEVEL</p>		<p>OD:</p> <ul style="list-style-type: none"> • Coordinate interdepartmental supporting actions.
<ul style="list-style-type: none"> • Current system structures do not support professional collaborations among multiple systems. 	<ul style="list-style-type: none"> • Provide TA to states to develop governance structures that support systems of care. • Offer incentive grants in order to motivate coordination across systems. • Insist on interagency collaboration and the system of care model when awarding federal departmental/agency grants, waivers, or cooperative agreements. • Coordinate among federal departments/agencies at the federal level. 	<p>SAMHSA:</p> <ul style="list-style-type: none"> • Utilize state infrastructure and other grants to help build state/county systems of care targeting this population. • Identify how current and planned SAMHSA—federal interagency efforts can increase collaboration and reduce duplications for this population. <p>ALL DEPARTMENTS:</p> <ul style="list-style-type: none"> • Assess how current and future funding can be used to provide incentive grants, support state and county interagency collaboration and coordination for this population.

PROVIDING MORE FLEXIBILITY FOR FINANCING SERVICES BASED ON NEEDS		OD: <ul style="list-style-type: none"> • Coordinate interdepartmental supporting actions.
<ul style="list-style-type: none"> • Financing mechanisms and community needs are not in alignment. • There is limited investment in screening, prevention and early intervention which are needed to end the ineffective and wasteful practice of addressing needs at the point of crisis. • There is limited state use of Medicaid waivers to help address the service needs of these children. • Private insurance shifts costs to the government. 	<ul style="list-style-type: none"> • Increase access for families to non-clinical supports such as in-home help, respite care, after school services, family support and advocacy. • Identify and remove federal barriers to braiding and blending funds. • Provide more flexible federal funding with the requirement to continue maintenance of effort and retain the entitlement nature of programs such as Medicaid and child welfare. • Provide Medicaid waivers for services across systems. • Provide clarification on Medicaid covered services. • Provide technical assistance to states and communities so they can use an array of financing approaches including risk-based to re-direct expenditures from the “deep end” or more expensive chronic and acute care services. 	ACF: <ul style="list-style-type: none"> • Look at IV-E waivers in the Children’s Bureau to determine ways to target coordinated financing for this population. CMS: <ul style="list-style-type: none"> • Investigate the concern that waivers are too categorical and are not offering the flexibility to fully address the complex needs of children with this class of disorders. • Explore issue of how co-occurring disorders could be incorporated into the Medicaid Disability Division’s Strategic Action Plan. • Assess how current round of system change grants might help address challenges of this population. • Assess impact of private insurance cost-shift to Medicaid and identify mechanisms to help address.

	<ul style="list-style-type: none"> • Eliminate the cost shift by insurance companies to the government/Medicaid. 	<p>SSA, ACF, CMS, HRSA, SAMHSA:</p> <ul style="list-style-type: none"> • Assess how more emphasis on providing families with purchasing power can enhance individual/family self-determination. <p>SSA:</p> <ul style="list-style-type: none"> • Investigate further how SSI might be used to relieve some of the constraints imposed by Medicaid in serving children with both developmental and emotional/substance abuse disorders. • Try to help the Office on Management and Budget (OMB) understand that it is economically wise to invest in screening, early detection and early intervention. • Seek guidance from other federal departments regarding data on cost benefit and specific recommendations for OMB. <p>ALL DEPARTMENTS:</p> <ul style="list-style-type: none"> • Identify how discretionary and categorical funding can include attention to financing strategies for this population group.
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SUPPORTING TECHNOLOGY AND RESEARCH		OD: <ul style="list-style-type: none"> Facilitate interdepartmental supporting actions.
<ul style="list-style-type: none"> There is a limited research on this population, effective treatments and service delivery systems within the public health system. There is limited data sharing, real time data utilization and supporting technology at the federal, state and community levels to enhance development of systems of care, clinical decision-making and performance monitoring tied to cross-system outcomes. 	<ul style="list-style-type: none"> Launch a public health approach to better understand this population. Support research that will foster a healthy growth of evidence-based practices. Develop clinical practice guidelines and quality monitoring systems tied to cross-system outcomes. Provide real time data across systems to support clinical decision-making, utilization management, and quality improvement. 	CDC: <ul style="list-style-type: none"> Consider coordination of an intergovernmental (e.g., with SAMHSA, ACF, CMS, NIH, SSA, DED, DOL, etc.) research/evaluation action plan, assessment of interdepartmental evidence based practices and public health awareness approaches targeting this population.

APPENDIX E: SUPPORTING STATE/COUNTY FINANCING DATA

COMPREHENSIVE AND COORDINATED SYSTEMS OF CARE: ELIGIBILITY AND ACCESS BARRIERS

Kenneth Ritchey, M.Ed., M.A.

*Director of Ohio Department of Mental Retardation
and Developmental Disabilities*

**Interagency Agreement Between
The Ohio Department of Mental Health
And
The Ohio Department of Mental Retardation and Developmental Disabilities
Concerning Ohioans with Mental Illness and Mental Retardation
or Developmental Disabilities**

I. PURPOSE

WHEREAS, persons with mental retardation or developmental disabilities and co-occurring mental illness are among the most vulnerable of Ohio's citizens, a cooperative effort among agencies is necessary to assist them to realize their maximum potential and live in the least restrictive setting consistent with their health and safety;

WHEREAS, the Ohio Department of Mental Health (hereinafter, "ODMH") is the executive agency granted authority pursuant to Chapter 5119 of the Ohio Revised Code to operate, license and/or certify programs for individuals with mental illness, and to provide regulatory oversight of the mental health functions of Alcohol, Drug Addiction, and Mental Health Services Boards and Community Mental Health Boards (hereinafter, "ADAMH/CMH Boards") which operate pursuant to Chapter 340 of the Ohio Revised Code; and,

WHEREAS, the Ohio Department of Mental Retardation and Developmental Disabilities (hereinafter, “ODMRDD”) is the executive agency granted authority pursuant to Chapter 5123 and Chapter 5126 of the Ohio Revised Code to operate, license and/or certify programs for individuals with mental retardation and developmental disabilities, and to provide regulatory oversight of County Boards of Mental Retardation and Developmental Disabilities (hereinafter, “County Boards”) which operate pursuant to Chapter 5126 of the Ohio Revised Code.

Now, therefore, ODMH and ODMRDD hereby subscribe to and support this “Interagency Agreement Concerning Individuals with Co-occurring Mental Illness and Mental Retardation or Developmental Disabilities.”

The specific purposes of this agreement are:

1. To find ways to most efficiently and effectively meet the needs of individuals with co-occurring mental illness and mental retardation or developmental disabilities;
2. To work together toward the implementation of identified best practices in all treatment and habilitation settings; and,
3. To develop and support a Coordinating Center of Excellence which will have the mission of further identifying best practices, including evidence-based practices, where they exist, training professionals in both systems, providing clinical consultation and follow-along throughout Ohio, and enhancing the ability of local systems to meet the needs of individuals served by both systems.

It is the goal of both departments to accomplish these purposes within available resources. It is also a goal of both departments to ensure that the above services are, to the extent possible, based on the needs of each individual.

II. JOINT RESPONSIBILITIES

- A. Each department shall appoint a person to serve as the primary contact or liaison. The liaisons shall have responsibility and authority for the following:

1. To serve as point persons for the two departments;
 2. To form committees or work groups to work on specific tasks;
 3. To provide information to the relevant personnel within their departments;
 4. To facilitate meetings between local persons or entities to accomplish the above purposes including, but not limited to, meetings between County Board personnel and ADAMH/CMH Board and provider agency personnel; and
 5. On an annual basis, to develop and revise a plan to provide joint training for individuals working in both systems, family members and consumers of services.
- B. The departments further agree to cooperate to:
1. Coordinate efforts to serve individuals with co-occurring mental illness and mental retardation or developmental disabilities;
 2. Develop and periodically revise training/informational materials concerning individuals with co-occurring mental illness and mental retardation or developmental disabilities;
 3. Assist communities, on a regional basis in developing joint proposals for programs including, but not limited to, long-term residential programs with intensive levels of supervision, and to seek funding for them in the biennial budget, or through grant proposals;
 4. Explore the development of an interagency group with the Departments of Education and Job and Family Services;
 5. Explore methods to best serve individuals who require competency restoration in order to stand trial, and to continue to serve those who are judged incompetent to stand trial-unrestorable; and
 6. Review and seek changes in relevant statutes and regulations, as needed.

III. RESPONSIBILITIES OF ODMH

- A. To identify individuals who have mental retardation or developmental disabilities in the Integrated Behavioral Healthcare System (hereinafter, “IBHS”);
- B. To adapt the programs as needed in IBHS to better meet the needs of individuals with a dual diagnosis of mental retardation or developmental disabilities and mental illness;
- C. To assure that Behavioral Health Organizations (hereinafter, “BHO”) staff working with dually diagnosed individuals demonstrate their competency to work with this population through the BHO competency assessment program;
- D. Within the parameters of state and federal laws relating to confidentiality:
 - 1. To assign staff at each IBHS facility the responsibility of attempting to maintain contact with a service and support administrator or other designated party from the County Board for the county from which the individual was admitted and to which he or she is likely to return;
 - 2. To provide relevant information and/or records to ODMRDD or a County Board prior to discharge so that the plan put in place upon discharge takes into account the most current information as far as the individual’s needs for behavior management, and his/her vocational skills, medical needs, and social skills;
 - 3. To determine if a person with mental retardation or a developmental disability has ever been served by ODMH or an ADAMH/CMH Board upon request from ODMR/DD; and
 - 4. To actively seek the services and support from ADAMH/CMH Boards when an individual with mental retardation or a developmental disability is identified as having mental illness;

- E. Within the IBHS, to administer the Ohio Eligibility Determination Instrument (hereinafter, “OEDI”), when requested by a County Board, for use by the County Board to determine eligibility for services and/or arrange for a County Board to administer the OEDI themselves;
- F. To provide or arrange for the provision of training programs for mental retardation/ developmental disabilities personnel in areas including, but not limited to, medication management, recovery, and non-medical clinical interventions;
- G. To promote the involvement of personnel from the ADAMH/CMH Boards and agencies in the treatment process as soon as County Board services are initiated;
- H. To provide or arrange for the training of mental health agency personnel to serve individuals with co-occurring mental illness and mental retardation or developmental disabilities;
- I. To act as a communication link between ODMRDD and ADAMH/CMH Boards and community mental health agencies; and
- J. To provide technical assistance relating to mental illness in the development of other specialized programs and facilities within mental retardation/developmental disabilities settings.

IV. RESPONSIBILITIES OF ODMRDD

- A. Within the parameters of state and federal laws relating to confidentiality:
 - 1. To determine if an individual with mental retardation or a developmental disability has ever been served by ODMRDD or a County Board upon request by ODMH;
 - 2. To determine if an individual is eligible for services from ODMRDD or a County Board and to administer or arrange for the administration of an OEDI for individuals upon request by ODMH or other agreed upon agent;

3. To provide or arrange for the provision of relevant records, if any exist, from ODMRDD or County Boards upon notice from ODMH that an individual with mental retardation or a developmental disability is being served by ODMH; and
 4. To actively seek the services and support from County Boards when an individual with mental illness is identified as having mental retardation or a developmental disability.
- B. To recognize that the residency of a person being served in an ODMH hospital, both during the hospitalization and upon discharge, will be determined in accordance with state laws and that provisions for housing and services on discharge are necessary to avert homelessness;
- C. To provide or arrange for the provision of training programs for state and local Mental Health personnel in areas including, but not limited to, identification of developmental disabilities, behavior management, vocational programs, and sexuality training;
- D. To promote the involvement of personnel from the County Board in the treatment process as soon as mental health services are initiated;
- E. To provide or arrange for the training of County Board service and support administrators and service coordinators to serve individuals with co-occurring mental illness and mental retardation or developmental disabilities;
- F. To act as a communication link between ODMH and County Boards and other local mental retardation or developmental disabilities agencies and providers;
- G. To provide technical assistance in regard to mental retardation/developmental disabilities in the development of other specialized programs and facilities within mental health settings; and
- H. To provide or arrange for the provision of training for ODMH personnel in the administration of the OEDI.

V. GENERAL PROVISIONS

- A. This agreement shall become effective upon execution and shall remain in force until June 30, 2005. At that time, ODMRDD and ODMH may renew this agreement for a two-year period on the same terms and conditions by giving written notice to the other party thirty days (30) before the expiration of the current agreement. All financial obligations of the departments under this agreement are subject to the appropriation of sufficient funds by the Ohio General Assembly. If at any time sufficient funds are not appropriated to continue funding the activities specified within this agreement, this agreement will terminate on the date the available appropriations expire without further obligation by either party.
- B. The obligations of the State of Ohio under this agreement are subject to the determination by the Directors of ODMH and ODMRDD that sufficient funds have been appropriated by the Ohio General Assembly to ODMH and ODMRDD for the purposes of this agreement and to the certification of the availability of such funds by the Ohio Director of Budget and Management as required by Section 126.07 of the Ohio Revised
- C. This agreement constitutes the entire agreement and understanding between the parties. Neither party may modify or amend the terms of this agreement, except in a written agreement signed by the parties' directors.
- D. This agreement may be modified or amended provided that any such modifications or amendment is in writing and is signed by the parties' directors.
- E. ODMRDD and ODMH, pursuant to Ohio Revised Code Section 125.111, agree that any subcontractor of ODMRDD and ODMH will not discriminate by reason of race, color, religion, sex, age, disability, national origin, or ancestry against any citizen of Ohio in the employment of any person qualified and available to perform the work under this agreement. ODMRDD and ODMH further agree that any subcontractor shall not, in any manner, discriminate against,

intimidate or retaliate against any employee hired for the performance of work under this agreement on account of race, color, religion, sex, age, disability, national origin, or ancestry.

- F. ODMRDD and ODMH agree to comply with all applicable state and federal laws regarding a drug-free workplace. ODMRDD and ODMH shall make a good faith effort to ensure that all of their employees, while working on state property, will not purchase, transfer, use or possess illegal drugs or alcohol or abuse prescription drugs in any way.
- G. ODMRDD and ODMH shall perform their obligations under this agreement in a manner that enables them to comply with their obligations under Subtitle A of Title II of the Americans with Disabilities Act of 1990, 42 U.S.C. Sections 12131 through 12134.
- H. The parties agree that they shall not use any information, systems, or records made available to either party for any purpose other than to fulfill the obligations specified herein. The parties agree to be bound by the same standards of confidentiality, which apply to the employees of either party and the State of Ohio.
- I. All notices required or permitted to be given by either party under the terms of this agreement shall be in writing; sent by certified mail, return receipt requested, or delivered in person; and
 - 1. With respect to ODMRDD, addressed to:
Ohio Department of Mental Retardation and
Developmental Disabilities
1810 Sullivant Avenue
Columbus, Ohio 43222
Attn: Deputy Director of Community Services
 - 2. With respect to ODMH, addressed to:
Ohio Department of Mental Health
30 E. Broad St. 8th Floor
Columbus, Ohio 43215
Attn: Medical Director

- J. This agreement will become effective upon execution. This agreement may be terminated without cause by either party, at any time, for any reason, by giving thirty (30) calendar days advance notice in writing to the other.

VI. Provisions for Compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA)

A. Definition

Protected Health Information (hereinafter “PHI”) is information received from or on behalf of ODMH and ODMRDD that meets the definition of PHI as defined by the Health Insurance Portability and Accountability Act (HIPAA) and the regulations promulgated by the United States Department of Health and Human Services, specifically 45 C.F.R. 164.501, and any amendments thereto.

B. Permitted Uses and Disclosures

ODMH and ODMRDD shall not use or disclose PHI except as provided within this agreement solely to fulfill the specific contract activities specified herein or as otherwise required under the HIPAA regulations or other applicable law. All subcontractors and agents of ODMH and ODMRDD are limited to the uses or disclosures that ODMH and ODMRDD are permitted by HIPAA to conduct.

C. Safeguards

ODMH and ODMRDD shall use appropriate safeguards to protect against use or disclosure not provided for by this agreement.

D. Reporting of Disclosure

ODMH and ODMRDD shall promptly report to the other parties of this agreement, any knowledge of uses or disclosures of PHI that are not in accordance with this agreement or applicable law. In addition, ODMH and ODMRDD shall mitigate any adverse effects of such a breach to the extent possible.

E. Agents and Subcontractors

ODMH and ODMRDD shall ensure that all of their agents and subcontractors that receive PHI from or on behalf of or create PHI on

behalf of ODMH and ODMRDD agree to the same restrictions and conditions that apply to ODMH and ODMRDD with respect to the use or disclosure of PHI.

F. Accessibility of Information

ODMH and ODMRDD shall make available to each other such information as they may require to fulfill their obligations to provide access to, provide a copy of, and account for disclosures with respect to PHI pursuant to HIPAA and regulations promulgated by the United States Department of Health and Human Services, including, but not limited to, 45 C.F.R. Sections 164.524 and 164.528 and any amendments thereto.

G. Amendments of Information

ODMH and ODMRDD shall make PHI available to each other in order for both of them to fulfill their obligations pursuant to HIPAA to amend the information and shall, as directed by each other, incorporate any amendments into the information held by each of them and ensure incorporation of any such amendments into information held by its agents or subcontractors.

H. Disclosure

ODMH and ODMRDD shall make available their internal practices, books and records relating to the use and disclosure of PHI received from each other, or created or received by either of them on behalf of the other, to each other and to the Secretary of the United States Department of Health and Human Services for the purpose of determining their compliance with HIPAA and the regulations promulgated by the United States Department of Health and Human Services and any amendments thereto.

I. Material Breach

In the event of a material breach of either ODMH or ODMRDD's obligations under this section, the other agency may at its option terminate this agreement. Termination of this agreement shall not affect any provision of this agreement which, by its wording or nature, is intended to remain effective and to continue to operate in the event of termination.

J. Return or Destruction of Information

Upon termination of this agreement, ODMH and ODMRDD, at their option, shall return to each other, or destroy, all PHI in their possession, and keep no copies of the information except as requested by each other or required by law. If either agency or its agent or subcontractor destroys any PHI then it will provide the other agency documentation evidencing such destruction. Any PHI maintained by either agency shall continue to be extended the same protections set forth in this agreement for as long as it is maintained.

K. Management and Administration

ODMH and ODMRDD shall permit each other to use PHI obtained from the other for management and administration purposes or to carry out legal responsibilities. ODMH and ODMRDD shall permit each other to disclose PHI obtained from the other if the disclosure is required by law or if the party disclosing the PHI obtains reasonable assurances from the person to whom the PHI is disclosed that it will be held confidentially and used or further disclosed only as required by law or for the purpose for which it was disclosed to the person and the person notifies the disclosing party of any instances of which the person is aware that the confidentiality of the PHI has been breached.

IN WITNESS WHEREOF, the parties' directors have executed this agreement on the dates shown below.

MICHAEL F. HOGAN, Ph.D., DIRECTOR
Ohio Department Mental Health
30 E. Broad St., 8th Floor
Columbus, Ohio 43215

KENNETH W. RITCHEY, DIRECTOR
Ohio Department of Mental Retardation
and Developmental Disabilities
1810 Sullivant Avenue
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Date: _____

Date: _____

Wright State University Project

This project's goal is to train psychiatric residents to work with individuals with mental retardation and developmental disabilities. Residents are placed in the County Board in order to gain experience with individuals with MR/DD. Outcomes for this project include training Montgomery CB staff in working with this population, teaching psychiatric residents to work with individuals with MR/DD, supervising psychiatric residents who are working with individuals with MR/DD, and providing direct services to individuals served by the Montgomery CB. ODMRDD, ODMH, Montgomery CB of MRDD, and the Montgomery County Board of Mental Health fund this project.

Glenn McCleese will track the stated outcomes.

Coordinating Center of Excellence for Dual Diagnosis

The CCOE will focus on system change. This would be accomplished by the development of local teams to better serve individuals with a dual diagnosis. The CCOE would provide training and consultation to these teams to improve services. In addition, the CCOE would be able to provide assessments of these individuals and conduct research around the types of services necessary to help this population be successful. ODMRDD, ODMH, and DD Council fund this project. The MI/MR Advisory Board would help provide some oversight to the CCOE. Glenn McCleese would track outcomes of the CCOE.

The Wright State project focuses on one aspect of the provision of services to individuals with a dual diagnosis, which is the training of psychiatrist.

The CCOE would focus on creating a local system of care for this population and provide the necessary training to create those systems.

Glenn McCleese will monitor both projects to ensure contract compliance.

INTEGRATING CARE FOR CHILDREN WITH SPECIAL NEEDS IN PUBLICLY FINANCED MANAGED CARE

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INTRODUCTION

“The world that we have made as a result of the level of thinking we have done thus far creates problems that we cannot solve at the same level at which we created them.” Albert Einstein

Throughout the last decade, there has been an explosion in the use of managed care technologies in the public sector—in State Medicaid programs, in State and local mental health and substance abuse systems, in public child welfare systems and in interagency systems of care operating at local levels.¹ At any given time in any given state or locality, there may be multiple managed care initiatives underway that are affecting subpopulations of the same children and families. Particularly for families who must rely on multiple public systems for services and supports, i.e. families of children with special needs, the cacophony of managed care reforms in states threatens to aggravate the fragmentation and confusion that, historically, have plagued children’s services.

¹ *Managed care* is defined here as the use of a variety of mechanisms designed to optimize the value of services provided by managing cost and utilization; these mechanisms, or technologies, include risk-based financing approaches, such as capitation and case rates, utilization management mechanisms, such as pre-authorization of care and concurrent utilization review, benefit management, provider profiling and credentialing, use of practice guidelines, level of care or patient placement criteria and preferred or exclusive provider arrangements. Any given public sector purchaser of managed care may be experimenting with some or all of these technologies.

This paper defines *children² with special needs* to include: children with emotional and behavioral (mental health and/or substance abuse) disorders; children with special physical health care needs; children with developmental disabilities; and children involved in child welfare and juvenile justice systems and their families—recognizing that there may be crossover among all of these populations. From a managed care design and purchasing standpoint, these populations of children and their families have service and/or system involvement that require degrees of customization over and above what is required by the larger population of children involved in public sector managed care. In most cases, managed care represents only one contractual slice of the health and behavioral health delivery system for children with special needs, and the more complex their needs, the more limited, historically, is the managed care slice.

In an effort to access health and behavioral health care, families of children with special needs often become involved, or are at risk for involvement, with multiple systems, including: Medicaid (and the State Children’s Health Insurance Program, if organized separately from Medicaid), mental health, substance abuse, health, maternal and child health (i.e. Title V), early intervention (i.e. Part C), mental retardation/developmental disabilities, child welfare, education and juvenile justice systems. Some children with special needs—but, by no means, all—also are eligible for Medicare and the Supplemental Security Income Program (SSI). For families who have a child with a serious or complex disorder, it is not any one agency but these multiple systems that make up the total health and behavioral health delivery system. Integration of care across these multiple systems, each supported by categorical funding streams, statutes and regulations, poses formidable technical and political challenges for state and local purchasers. This, historically, has been true in fee-for-service systems and continues to be the reality in a managed care environment.

In response to the fragmented nature of the total health and behavioral health delivery system, there has been a movement in the public sector over

² Children are considered here to include the 0 to 3 year old, 3-5 year old, 6-12 year old, 13-18 year old and the 18-21 year old transition populations.

the past 15-20 years to develop “systems of care” for children with special needs and their families. *A system of care is defined here as a broad array of services and supports that is organized into a coordinated network, that integrates care planning and management across multiple systems and that builds meaningful partnerships with families at service and policy levels.* While systems of care may be developed on a statewide basis, they are intended to operate locally.

The system of care movement fundamentally is concerned with improving service integration, coordination of care and cost and quality outcomes. These goals are similar to those that many State Medicaid managed care reforms have for a larger population of children and families (within which are included subpopulations of children with special needs and their families). In recent years, systems of care serving children with special needs have adopted managed care technologies, such as case rate financing, organized provider networks, care authorization and care management, and utilization and outcomes management, recognizing the potential of these technologies to lead to better integrated care. In many states, however, local systems of care (whether using managed care technologies or not) are not connected to larger State managed care initiatives, such as those occurring in Medicaid, mental health or child welfare systems, even when those reforms share certain goals with systems of care and are serving many of the same children.

There is an irony to the disconnect that occurs in States between large-scale managed care reforms and local system of care initiatives. Managed care is a technology with considerable potential to improve service integration, care coordination and cost and quality outcomes, particularly for “high utilizers” of services, such as children with special needs. While publicly financed managed care may be approaching this potential, particularly for non high using populations, within any given public system—for example, within State Medicaid programs or within State mental health or child welfare systems—it is in danger of aggravating attainment of these goals across the total delivery system on which children with special needs rely. In addition, systems of care, which focus on improving outcomes for high utilizing populations within the context of the total delivery system, and which,

increasingly, make use of managed care tools, are in danger of being marginalized by larger State managed care initiatives.

Increasingly, state and local officials, managed care organizations, families, providers and advocates are becoming aware of these issues. In a number of states and locales, these stakeholders are struggling in a deliberate fashion with how to achieve better service integration and outcomes for children with special needs and their families within the total delivery system in a managed care environment, and some are implementing promising approaches.

A fundamental question facing state purchasers is the degree to which the customization required by children with special needs should and can occur within the managed care system or should remain outside the system, with clearly defined pathways between what is built in or kept out. Systems of care are, by definition, *customized* approaches to integrating care for children with special needs and their families. Where they exist or can be developed, they offer an approach, through inclusion in or formal linkage with large-scale managed care, to improve service integration for children with special needs.

The purpose of this paper is to explore some of the issues and challenges facing states in this area and raise the potential for fit between large-scale public sector managed care initiatives and systems of care focusing on subpopulations of children with special needs. The paper hopes to stimulate new ways of thinking about both managed care and systems of care so that the potential of both may be realized. From a family's standpoint, the total delivery system should look more seamless, rather than more fragmented, as a result.

TODAY’S UNIVERSE OF PUBLIC SECTOR MANAGED CARE AND SYSTEMS OF CARE

What Exists Today?

While there are variations on the following—and categorizations of public sector managed care tend to be problematic as a result—currently, there are essentially the following types of managed care initiatives, as well as systems of care, underway in the public sector that affect children with special needs:

- ***Medicaid Managed Care: Integrated Physical Health/Behavioral Health Designs***

These initiatives combine Medicaid inpatient and outpatient dollars for physical health and behavioral health services, typically in a traditional HMO approach, utilizing capitation financing, although these integrated approaches may also offer the option of enrollment in a primary care case management (PCCM) program, which creates an accountable “gatekeeper” and care manager but without assigning full risk. Integrated approaches tend to most resemble commercial sector managed care, with an acute care and “medical model” focus, and most utilize commercial managed care companies. Most of these integrated Medicaid managed care reforms have a fairly traditional, limited behavioral health benefit, covering, for example, 30 outpatient visits and 20 inpatient days, and most, predominantly, focus on physical health concerns. State Medicaid agencies tend to have sole policy authority over integrated designs. Extended health and behavioral health care delivery systems, including those supported by Medicaid rehabilitative services dollars, tend to remain outside these integrated managed care designs, continuing to operate on a fee-for-service basis (if they are not included in a carve out—see below). The target population in integrated designs includes primarily the Medicaid-eligible population, or subgroups thereof, and about half also include the SCHIP population. Integrated reforms are less likely than carve outs to cover the entire Medicaid population, but, increasingly, are enrolling high utilizing populations, including the SSI population and children involved in child welfare.

- ***Medicaid Managed Care: Behavioral Health and Other Service Carve Outs***

Behavioral health carve outs (which “carve out” behavioral health financing and administration from physical health in a separate managed care arrangement) utilize Medicaid inpatient and outpatient dollars, often Medicaid rehabilitative services dollars and, sometimes, behavioral health block grant and/or general revenue dollars, in a variety of managed care approaches. They utilize a variety of entities, including commercial companies, nonprofit agencies, such as community mental health centers, and government agencies, as MCOs. They typically employ capitation but may also use case rate financing. While some behavioral health carve outs provide only acute care, some (certainly those that are utilizing rehab services dollars) provide extended care as well. As discussed more fully later, however, even those that are providing extended care tend to leave some behavioral health treatment dollars (including Medicaid dollars) outside the managed care reform, typically within child welfare, juvenile justice and/or education systems. Unlike integrated designs, carve outs tend to cover a fairly broad array of services, including many of the services found in systems of care, such as intensive case management, in-home services and wraparound supports. Typically, State Medicaid agencies and State behavioral health agencies share policy authority over carve outs. The target population in carve outs includes the Medicaid-eligible population, including, in most cases, the disabled population, and children involved in child welfare. Some carve outs also are covering non-Medicaid populations who depend on public systems, including the uninsured and families who exhaust their private coverage. In addition to behavioral health carve outs, there are a handful of other types of service carve outs, such as diabetes care management, but the behavioral health carve outs have the longest “reach” in their impact on children with special needs.

- ***Population Carve outs***

A number of states and counties are using managed care approaches to improve cost and service outcomes for defined, high utilizing subpopulations of children and adolescents involved in, or at risk for involvement in, “high end” or “deep end” services. Deep-end services

refers to the most restrictive, and, usually, most expensive, types of services, such as residential treatment and inpatient hospitalization. These “population carve outs” may cover, for example, children with serious emotional disorders, children eligible for Title V CSHN programs, the SSI population. Typically, these approaches are being piloted in states around relatively small subpopulations of children and families, for example, 300 children in a county or service area. They often combine funds from across children’s systems, including Medicaid dollars, an approach that is referred to in this paper as “blended or braided funds”, and tend to use case rate, rather than capitation, financing. They tend to cover a very broad, flexible array of services and supports, and often have interagency policy or governance structures that include family representation. Systems of care that are using managed care technologies fall into this category.

- ***Child Welfare Managed Care***

A number of states have begun to experiment with utilizing managed care approaches in the child welfare arena, typically to prevent or reduce lengths of stay in out-of-home care. These initiatives tend to use child welfare dollars (Title IV-E and IV-B and child welfare general revenue), may also use Medicaid dollars and are experimenting with a variety of managed care approaches.³ Typically, they are using case rate, rather than capitation, financing approaches. Commonly, child welfare managed care uses a lead agency approach, in which non profit agencies assume certain managed care functions, such as service authorization and provider network oversight, with a commercial managed care company providing administrative support (ASO) functions. Child welfare managed care typically covers a broad range of services, including behavioral health treatment services, and public child welfare systems usually have policy authority over these reforms. The target population for child welfare managed care initiatives typically includes children in, or at risk, for out-of-home placement as a result of abuse or neglect.

³ See, for example, the Kansas Child Welfare Privatization Initiative, the Massachusetts Commonworks Initiative and the Hamilton County, Ohio Managed Care Initiative.

- ***Systems of Care***

A number of states and counties, as noted earlier, are developing “systems of care,” which are defined as a comprehensive spectrum of services and supports which are organized into a coordinated network across multiple systems to meet the complex and changing needs of children and adolescents with special needs and their families. Many system of care demonstrations have grown out of federally funded initiatives, such as the Child and Adolescent Service System Program (CASSP), the Children’s Mental Health Services (CMHS) Program and the Title V Children with Special Health Needs Program, as well as foundation-supported efforts, such as the Robert Wood Johnson Foundation’s Mental Health Services Program for Youth (MHSPY Project). Systems of care emphasize collaboration across categorical agencies, a single plan of care, one accountable care manager, individualized services and supports that are “wrapped around” children with special needs and their families, home and community-based alternatives to hospital and institutional settings, cultural competence and partnership with families in the design and delivery of care.

Systems of care may or may not be using managed care approaches, but like the managed care initiatives for “high utilizing” populations described above, they tend to focus on children who are involved, or are at risk for involvement, in deep end services. Similarly, they tend to blend or access funds from across children’s systems to support a broad, flexible array of services and supports, and are focusing on a relatively small target population in a given locale. Like their counterpart above, they also tend to have interagency policy bodies with family involvement.

Any given state, at any given time, may have all four types of public sector managed care underway as described above, as well as systems of care. Although there is cross over among the populations each serves, each may be planned and operated on separate tracks.

Disconnect Between Managed Care and Systems of Care

There are structural, philosophical and political reasons underlying the disconnect that may exist in states between large-scale managed care initiatives, such as Medicaid managed care, and system of care initiatives.

For example, in some states, large-scale managed care initiatives may be designed structurally as acute care reforms, providing brief, short term treatment for a total eligible population of children (for example, all Medicaid eligible children). Systems of care are usually designed to provide extended care to a smaller subset of a total eligible population (for example, children who have serious disorders). Managed care initiatives in these instances may be using “acute care” dollars, while systems of care are using extended care dollars.

Philosophically, large-scale managed care initiatives may employ more of a medical model approach, applying more narrow medical necessity criteria than would be used in systems of care that are using more of a psycho social necessity approach. Large-scale managed care networks may include primarily traditional clinical services, while systems of care are utilizing a broad array of both traditional clinical services, home and community-based services and natural supports. Additionally, managed care may have less of a focus on family involvement at both service and systems levels than systems of care, and less of a focus on cultural competence at all levels of the system. For example, research has found that family involvement in Medicaid managed care reforms, particularly in integrated physical/behavioral health designs, primarily is concerned with involving families in treatment planning for their own children, while systems of care seek to involve families at all levels as partners in system and services implementation. Similarly, cultural competence in managed care concerns itself primarily with such matters as having bilingual providers and materials translated, while systems of care seek to infuse cultural competence into all levels of systems and services operations.⁴

Politically, managed care tends to be driven and governed by state Medicaid agency concerns and policies, which, at this stage at least, tend to focus more on access and cost outcomes than do systems of care, which are more concerned with improving services integration and child/family functional outcomes. While they may involve state Medicaid agencies, systems of care tend to be driven and governed by children’s agencies.

⁴ See, for example, Pires, S., Stroul, B., Armstrong, M. *Health Care Reform Tracking Project: 1999 Impact Analysis*. 2000. University of South Florida: Tampa, FL

While there remains a disconnect between systems of care and large-scale managed care reforms in many states, they are not, inherently, opposing forces, and, developmentally, both may have reached a stage where they can inform each other. As noted, systems of care are gaining familiarity with managed care technologies, and large-scale managed care initiatives, as they increasingly enroll populations of children with special needs, can learn from the experience of systems of care, which are tackling some of the issues and challenges involved in integrating care for children with special needs and their families. As discussed in Sara Rosenbaum’s accompanying analysis, through their purchasing specifications, states are experimenting with a variety of ways to customize care that include aspects of systems of care.

EXPLORING ISSUES AND CHALLENGES

Population Issues

Who Depends on Public Systems?

One of the first challenges to designing a more integrated delivery system for children with special needs within managed care is defining the population. To reach a definition of children with special needs, one must begin with a picture of who the total population is that depends on public systems for services and supports, within which are subpopulations of children with special needs. The total population includes:

- children eligible for Medicaid and the State Children’s Health Insurance Program (SCHIP)
- low income and uninsured families who do not qualify for Medicaid or SCHIP
- families who are privately insured but who exhaust their private insurance coverage, typically because they have a child with special needs
- families who are privately insured and who, while not exhausting their private coverage, need a particular type of service for their child that is not available through their commercial insurance and is only available in the public sector, again, typically, a family of a child with special needs.

Because private insurance rarely covers more than brief, short term health and behavioral health care, families who have a child with a serious or complex disorder, regardless of income, typically end up having to turn to the public sector, along with families who are poor or uninsured and for whom the public system is the only option.*

Disaggregating the Population

In thinking about how to design a delivery system for the total population of children that depends on public systems, within which there are subpopulations of children with special needs, it is critical to disaggregate both the total population and the subpopulations by certain characteristics—i.e. by population, service and system involvement characteristics. In so doing, managed care designers and purchasers can begin to define subpopulations of children who require customization and the degree of customization entailed. Closer analysis of population characteristics can support more informed cost and quality benefit analyses regarding what to customize within managed care and what to leave outside of managed care with clearly defined pathways between the two. For example, within the total eligible population is a subpopulation of children who have behavioral health problems. This subpopulation can be further disaggregated to include children who have need for only brief, short-term treatment, those with intermediate care needs and those requiring extended services and supports. Creating a traditional benefit package of limited outpatient and hospital care may suffice for the subpopulation needing only short-term treatment, but will not be adequate for the rest.

*There is a tacit understanding in our health care delivery system that the private sector will shift to the public sector families needing extended care. There is less tacit agreement, however, that the private sector also should shift to the public system families who have not exhausted their private coverage but who need a particular type of service not available through their commercial carrier—for example, a family that needs a behavioral aide in the classroom or in-home support for a relatively brief period of time to stabilize an acute care situation, but who can access only office-based outpatient counseling and/or inpatient hospitalization through their commercial carrier. If private insurers could be persuaded to cover a broader array of services, including non traditional services and supports, even in an acute care context, it would help to alleviate some of the pressure on public systems and reduce the need for families to have to turn to the public system simply to access a particular type of service. Nor should it be a foregone conclusion by commercial carriers that expansion in the array of covered services and supports for this population will necessarily increase their costs. Based on public sector experience, the jury seems to be still out on that question. Certainly, some Medicaid managed care programs that have expanded a traditional benefit package to one that includes a broad array of managed services and support have held costs steady, even while increasing utilization. (Readers also are referred to a Rand Corporation study that found only slight direct cost increases to employers associated with an unlimited substance abuse benefit and indirect cost savings through enhanced productivity and fewer employee absences. *Managed Behavioral Health News*. June 1999. Vol. 5. No. 23.)

Similarly, within the total eligible population are families who are involved with the child welfare system. These include families who have come to the attention of child protective services, those who are foster parents, adoptive parents of special needs children and those who have become involved in the system to access a particular type of service, such as therapeutic foster care. Within the subpopulation of children and families involved in the child welfare system, there tends to be an over- representation (in comparison to the total population dependent on public systems) of certain children and adolescents and of particular service needs. For example, child welfare systems today are serving a disproportionate number of infants and pre-schoolers at risk for emotional and developmental delays; there are disproportionate numbers of older adolescents who are transitioning out of foster care; there are a disproportionate number of families in which substance abuse is an issue; and there are disproportionate numbers of children with dual diagnoses of emotional and developmental disorders, with conduct disorders, with sexual impulse control issues and with sexual abuse treatment needs. In addition, children in the child welfare system require customized responses because of the nature of the system in which they are involved. For example, due to multiple placements, they are far more mobile than the total population that depends on public services, safety and permanence are critical issues, and the courts play a role in the lives of many of these children and families.*

The total eligible population includes other sub-populations of children who bring unique characteristics. For example, there are significant percentages of children and adolescents who are involved in the juvenile justice and special education systems, for whom there also are unique population, service and system characteristics. There are children with special physical health care needs and with developmental disabilities, and there is tremendous variation in service use and cost depending on type of disability or disorder. For example, recent studies indicate that inpatient costs represent about 83% of total costs for children with chronic respiratory disease, but only 28% of the total cost of care for children with cerebral palsy.⁵ There are also, of course, significant percentages of children with dual or multiple disorders, for example, children with behavioral health and developmental disorders.

The unique characteristics of the various subpopulations of children within the total eligible population carry implications for a host of system design and purchasing variables—e.g. for the types of stakeholders that need to be at the system design table; for the types of services and supports that are included in managed care arrangements; for the types of providers that are involved in networks; for the relationships that have to be in place with juvenile court judges, with child protective services workers, with probation

*A recent analysis of children in foster care in San Diego County, California, provides insight into the unique population, service and system characteristics of the child welfare population that must be factored into managed care design for a total eligible population of children and adolescents. The study examined rates of mental health problems in the foster care population, rates of service use and predictors of care. Among the findings were the following:

Population Characteristics

- Over 50% of children entered foster care prior to school age.
- African American children were five times over represented in the foster care population, that is, African American children represented 32% of the foster care population but only 5% of the total child population in the county.
- Caucasian children were under represented in the foster care population relative to their distribution in the total child population.
- Fifty-four percent of children entered foster care for reasons of neglect; 20% for physical abuse and 11% for sexual abuse.
- Two out of three children, age six and under, tested in the abnormal developmental range.
- Fifty percent of children, age 4 and over, needed services for behavioral health problems; sixty percent for social competence.
- Three out of four children, age 4 and over, were in the problem range for behavioral or social competence. There were not significant differences across racial groups with respect to need for services.

Service Characteristics

- Access to screenings through the child welfare system was not an issue, but access to appropriate services was.
- Most children who received services received only office-based outpatient treatment delivered by psychologists. The mean number of outpatient visits was 14.
- There was little use of in-home or group services due to limited access.
- Predictors of service use were in order: sexual abuse; physical abuse; and age (i.e. adolescents).
- Children involved in foster care for reasons of neglect were the least likely to receive services.
- A slightly higher percentage of Caucasians than African Americans received services.

System Characteristics

- The Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program identified fewer than 1% of children in foster care who were in need of services.
- Service data from the child welfare system were of poor quality. (Landsverk, J. and Garland, A.F. "Foster Care and Pathways to Mental Health Services". In: *The Foster Care Crisis: Translating Research into Prevention and Policy*. P.A. Curtis, G. Dale, Jr., and J.C. Kendall (Eds). 1999. Lincoln: University of Nebraska Press.)

These characteristics are not unique to San Diego. For example, a study of 40,000 children on Medicaid in Pennsylvania, comparing utilization of mental health services between children in foster care and those on welfare (prior to welfare reform), found much higher rates of utilization by children in foster care. The study found that mental health utilization rates of children in foster care were roughly comparable to utilization rates of children receiving SSI. (Harman, J., Childs, G. and Kelleher, K. *Archives of Pediatrics and Adolescent Medicine*. November 2000. Vol. 154).

⁵ Ireys, H. et. al. *Cost of Care for Medicaid-Enrolled Children with Selected Disabilities*. May 1996. Available at <http://aspe.hhs.gov/daltcp/reports/carctses.htm>

officers, with special education placement processes; and for governance and liability arrangements. Population characteristics also need to inform determination of capitation and/or case rates and risk structuring, including the need for particular types of risk adjustment mechanisms. The greater State purchasers' understanding of the unique characteristics of children with special needs, the more informed decisions they can make about whether and what to customize within managed care and what to leave outside of managed care that will require defined coordination pathways.

How Children Use Services

In addition to understanding who uses public systems, it also is helpful to examine how children with special needs tend to use services. Typically, within the *total* population of children who depend on public systems, while there may be regional variation, most children—60-70%—will require no more than brief, short term care. For most of these children, managed care arrangements in Medicaid and in mental health seem to be improving access to services. For the remaining 30-40% of children, however, those who require intermediate to extended health and behavioral health care, (which includes children with special needs), managed care in these systems, for the most part, has done little to clarify, and, in some cases, has aggravated, accountability for service provision across children's systems (although managed care is focusing greater attention on the fragmentation problem).⁶ This is particularly the case for the 7-10% of families who have a child with a serious health or behavioral health disorder, who require an array of services and supports, at varying times and in varying intensity, over an extended period of time and who, typically, utilize about 70% of the resources in state systems. Managed care reforms in Medicaid and in mental health agencies are not managing *total* health and behavioral health care for these highest utilizers of services. Systems of care, where they exist, may be managing total care for these families and children, but are more likely to be sharing service responsibility with State Medicaid or mental health managed care systems that retain acute care responsibility. Typically, the

⁶ See, for example: Pires, S., Stroul, B., Armstrong, M. *Health Care Reform Tracking Project: 1999 Impact Analysis*. 2000. University of South Florida: Tampa, FL

pathways between the acute care systems and extended systems of care have not been clarified, leading to the potential for (and accusations of) cost shifting, as well as confusion for children and families.

The fragmentation in service delivery for children with special needs within managed care systems must be put into the historical context of the fragmentation within fee-for-service systems. Managed care, unlike fee-for-service systems, at least carries the potential, and, in some cases, the reality of more integrated care. For example, managed care systems can create medical homes or lead agencies to coordinate care, and waivers that enroll children with special health care needs in managed care are required to incorporate care coordination and coordination with health services outside the boundaries of managed care that receive federal funding.

Looking at how children in the total population use services carries implications for system design. Specialized features, beyond what is designed for the majority of families with brief, short-term needs, have to be incorporated into the system for families who have children with intermediate to extended care needs. These features might include, for example, wholesale inclusion or development of systems of care within the total system, or if not inclusion, creation of clearly defined pathways to extended care from acute care systems.

Financing Issues

What is Being Depended Upon?

The fundamental challenge to creating an integrated, managed delivery system for children with special needs and their families is the multiple, categorical nature of children's financing streams and delivery systems in the public sector. The following table presents a picture of various financing streams that support health and behavioral health services in the public sector. It may not be a complete picture in some states and it may overstate the number of funding streams in others, but on balance, it is a representative depiction.

**Examples of Health and Behavioral Funding Streams
for Children in the Public Sector**

Medicaid

Medicaid Inpatient
Medicaid Outpatient
Medicaid Rehab. Services
EPSDT

Mental Health

MH Gen'l. Revenue
MH Medicaid Match*
MH/SA Block Grant

Child Welfare

CW Gen'l. Revenue
CW Medicaid Match
IV-E
V-B
Family Pres./Support

Juvenile Justice

JJ Gen'l. Revenue
JJ Medicaid Match (GR)

Education

Spec. Ed. Revenue
ED Gen'l. Revenue
ED Medicaid Match (GR)

Health

Title V
Part C-Early Identification

State Children's Health Insurance Program (SCHIP)**Other**

Substance Abuse General Revenue and Medicaid Match (GR)
Mental Retardation/Developmental Disabilities General Revenue and Medicaid Match (GR)

*Medicaid match dollars are general revenue dollars allocated as Medicaid match.

Delivery Systems Supported by Different Financing Streams

Typically, each of these funding streams supports a distinct service delivery system, although, from a family's standpoint, the systems appear to overlap, and there often is confusion as to which delivery system should be accessed at what stage. Some of these funding streams support acute care systems only (i.e. brief, short-term treatment); others support more extended care systems. Typically, the pathways between the acute care systems and extended care are unclear, and, typically, the extended care systems form, *in toto*, their own irrational "system". For example, a family with private coverage, who is not involved with the child welfare or juvenile justice systems but who has a child with a serious behavioral health disorder, may turn to the mental health system or special education system for services if their private coverage is exhausted or if it will not cover a particular type of service. If services are not available through those systems, families might then have to turn to the child welfare system, sometimes being required to relinquish custody of their child to obtain services from that system. The youngster in that family might also end up in the juvenile justice system,

particularly if services cannot be obtained and behavioral problems escalate. For children with special needs, this is not an uncommon scenario but certainly an irrational one.

Each of these funding streams also tends to support distinct contracting arrangements, although there may be overlap among the contracted services each funding stream is supporting. Providers often have separate contracts with several of these systems, each with different contractual requirements, even though, sometimes, the same services are being purchased and the same children are being served.

Each of these funding streams is handled differently in each state, depending upon state structure and policy. Some states, for example, decentralize some of these funds to counties; others centralize administration of funds. If decentralized, funds may be administered differently in each county.

It is impossible to understate the politics that surround categorical funding streams and delivery systems at state and local levels. The public agencies that control these funds and the providers and consumers who depend upon them often guard their distribution, or re-distribution, closely, even when there is political rhetoric for more integrated service delivery. The fears of agencies, providers and consumers of letting go of these monies are not necessarily unfounded. The history of block granting formerly categorical monies, for example, too often has been associated with fund erosion. On the other hand, the newer generation of “blended or braided funding”, found predominantly in systems of care, demonstrates the possibility of achieving more rational, integrated (whether “virtually” or actually integrated) financing arrangements for children with special needs and their families. Perpetuation of categorical financing, however well intended, also perpetuates the fragmentation in children’s services.

In addition to the politics surrounding categorical funding streams, the distinct legal and administrative requirements attached to each pose technical barriers to integration. However, the potential also exists at federal, state and local levels to waive many of these requirements, and the

fact that some jurisdictions have done so, albeit on a small scale, holds promise for more widespread systemic flexibility.

Which Types of Dollars Are Used in Managed Care?

Theoretically, managed care could be a powerful tool for de-categorizing dollars. Capitation and case rate financing allow for flexibility in dollar allocation in exchange for meeting specified outcomes. In reality, however, most public sector managed care initiatives to date utilize only a handful of categorical funding streams; they may introduce flexibility into the disbursement of one or two streams but do very little to create flexibility across the multiple funding streams for children. In fact, because any given managed care initiative tends to harden the boundaries around the particular dollars it uses, managed care, ironically, may aggravate the categorical nature of children's spending.

A study focusing on behavioral health managed care in the public sector, principally Medicaid managed care, found that, of ten states studied in 1997, all ten left outside their Medicaid managed care systems various behavioral health financing streams for children. Six of the ten states designed their initiatives to provide only acute care, using only Medicaid outpatient and inpatient dollars. Four of the ten (all behavioral health carve outs) incorporated both acute and extended care into their Medicaid reforms, using, typically, Medicaid outpatient, inpatient, rehabilitative services and, in some cases, behavioral health general revenue and block grant monies. Even these four, however, left behavioral health treatment dollars in other child-serving systems, typically in child welfare, juvenile justice and/or special education, even though children involved in those systems were enrolled in managed care. More recently, the study found that of 35 Medicaid managed care reforms in 34 states, 32 (91%) left Medicaid fee-for-service dollars outside of the managed care system in other children's systems (i.e. in education, child welfare, juvenile justice, children's mental health and mental retardation/developmental disabilities).^{7,8}

⁷ Pires, S, Stroul, B, Armstrong, M. *op. cit.*

⁸ Stroul, B., Pires, S., Armstrong, M. *Health Care Reform Tracking Project: 2000 State Survey*. 2001. University of South Florida: Tampa, FL

As noted, there are a host of political, policy and operational reasons as to why categorical financing streams are left outside managed care initiatives, including the legitimate desire to leave a “safety net” in place for children with serious disorders. *However, this desire says more about the historical difficulty managed care has had in effectively serving children with serious disorders than it does about its potential to lead to better care.* Stakeholders in all ten states noted above reported that the managed care design’s failure to integrate acute and extended care financing streams was aggravating fragmentation, duplication and confusion in children’s services. At the same time, stakeholders expressed serious reservations about whether managed care could or would be designed and implemented in ways that protected the most vulnerable children and families. This ambivalence has led to a kind of stasis in some states in which managed care continues to be designed and implemented in fairly traditional fashion patterned after the commercial sector, in response to which categorical systems become ever more turf protective. In some states and counties, however, stakeholders across systems have entered into partnerships with plans, providers and families to try to activate the potential of managed care to improve service integration by drawing on multiple funding streams through blended or coordinated funding approaches.

Data Issues

Another major challenge to integrating care for children with special needs in managed care is the relative unavailability of data that provide a true picture across the total delivery system of how many children (and which children) with special needs use services, which services they use, how much they use and how much service costs. Like the dollars, data tend to be spread across multiple systems, may be of poor quality or simply are not captured in a way that is useful for managed care design and purchasing purposes. Child welfare and juvenile justice systems, for example, often do not disaggregate health and behavioral health expenditures from larger service contracts. Medicaid agencies typically do not capture general revenue and other expenditures for health and behavioral health spent by other systems that are not Medicaid match dollars. Medicaid service utilization data for the SSI population, for example, picks up only a fraction

of service use by children with special needs because many children with special needs cannot qualify for SSI, in spite of serious disorders and heavy service use. A recent analysis of Medicaid expenditures conducted by the federal Substance Abuse and Mental Health Services Administration, for example, found that among children and adolescent “high cost” users of mental health and substance abuse services paid for by Medicaid, only one third were SSI recipients.⁹ The rest fell into other Medicaid eligibility categories and would have been missed by an SSI carve out seeking to manage care for high utilizing Medicaid populations.

Rate and Risk Structuring Challenges

Not surprisingly, given the lack of data providing a reliable picture of service utilization and cost by children with special needs and the multiplicity of agencies and funding streams involved in their care, rate and risk structuring is another challenge. There are a few models for rate and risk structuring for discrete subpopulations of children, for example, for the child welfare population, for children with serious emotional disorders and for certain populations of children with special physical health care needs. However, there are not reliable, tested models for rate and risk structuring across a total eligible population that includes the subpopulations of children with special needs defined in this paper. The variability within the subpopulations of children with special needs makes rate and risk structuring difficult, as does the so-called “woodwork effect” (that is, accounting in rate and risk structuring for a surge in demand in response to the availability of a more integrated system of care).

The traditional rate structuring approaches that are based on age, gender and demographics are not sufficient for children with special needs populations. Reliable rate structuring for these populations is more likely to be based on clinical or functional status and/or diagnostic criteria. It may be possible to utilize the experience of states that have developed risk adjusted rates and risk sharing arrangements for discrete subpopulations of children (e.g.

⁹ Buck, J. *Medicaid and Children's Mental Health Services*. 2001. Center for Mental Health Services. Substance Abuse and Mental Health Services Administration: Rockville, MD.

children involved in child welfare) to begin to develop total population rate and risk structuring approaches. This experience includes both systems of care and managed care initiatives that are using case rates, rather than capitation, for subpopulations of children with special needs, and a variety of risk sharing arrangements, including risk pools, reinsurance, risk corridors and the like. It has been argued that, for children with special needs, case rates inherently make more sense than capitation rates since these are children who *will* use services.^{10,11} Risk-based financing will not have much impact on whether these children use services but can affect the types and amount of services that they use. For example, early intervention and crisis planning might prevent use of emergency rooms and hospital beds; home and community based alternatives might prevent more costly use of inpatient and residential care.

In addition to rate and risk structuring at the MCO level, customization also is necessary with respect to compensation arrangements at the provider level. For example, compensation needs to factor in the costs associated with the time providers spend having to coordinate care across multiple providers and systems and working with families to increase their knowledge and capacity to care for their children.

Benefit Design Issues

Children with special needs also require customization of the benefit package. The more traditional the benefit design (i.e. the more it resembles a commercial managed care package), the more customization will be required. The system of care movement suggests that children with special needs require access to a broad benefit design, one that covers a broad array of services and supports (including informal and natural supports). Systems of care also suggest that the benefit needs to be flexible, i.e. not constrained

¹⁰ Broskowski, A. *The Role of Risk Sharing Arrangements*. 1998. In: *Managed Care: Challenges for Children and Family Services*. Annie E. Casey Foundation: Baltimore, MD.

¹¹ Capitation pays MCOs or providers a fixed rate per *eligible* user of service, while case rates pay a fixed rate per *actual* user of services, based typically on the service recipient's meeting a certain service or diagnostic profile. In a capitated system, a potential incentive is to prevent eligible users from becoming actual users. In a case-rated system, there is no such incentive, although case rates do create an incentive (like capitation) to control the type and amount of service.

by artificial day or visit limits, to support an individualized, “wraparound” approach to service delivery, which is needed by children who have multiple and complex issues and whose needs change frequently as children develop over time. Additionally, the manner and setting for service delivery must go beyond the medical model approach of physician office, outpatient clinic and hospital based care to encompass non traditional and natural settings, including home and school.

Precisely because it incorporates management mechanisms, such as utilization management, managed care offers the potential for states to cover a broad, flexible array of services and supports while controlling cost, and some states, particularly carve outs, are doing so. In some cases, the degree of customization may be greater than some state purchasers are willing or able to undertake. In that event, clearly defined pathways are needed between the services and supports covered under managed care and those available through other child-serving systems. If state designers take a population focus and consider the total delivery system as defined here, they can make more informed decisions about what to purchase within managed care and what to leave outside with coordination pathways in place.

Another challenge is to allow “room” within the benefit design for incorporation of efficacy-based treatment approaches. New data are continually emerging regarding treatment approaches that show promise for different subpopulations of children with special needs. These treatment approaches may look very different from what managed care typically has covered. For example, recent studies pertaining to children’s behavioral health treatment indicate that there is the least amount of efficacy data for those services on which there has been, historically, the most reliance for children with serious disorders, namely, inpatient hospitalization and residential treatment. Conversely, there is increasing evidence of treatment efficacy for some newer approaches, such as Multi-Systemic Therapy, an in-home service approach, and intensive case management approaches.¹²

¹² Burns, B., Hoagwood, K. & Mrazek, P. *Effective treatment for mental disorders in children and adolescents*. 1999. Clinical Child and Family Psychology Review. 2(4), 199-254.

Enrollment and Disenrollment Issues

Children with special needs encounter unique enrollment and disenrollment issues over and above those faced by the general population enrolled in managed care. Identification and enrollment of children with special needs may call for customized approaches beyond what is put in place for the larger population. For example, there are existing, federally mandated structures in place in states to find, screen and assess children with special needs, including EPSDT, Part C (early intervention) programs, Title V and other “child find” efforts. There are no doubt differences among the screening and assessment instruments being used within the managed care system and these other programs, which pose integration challenges. If not incorporating these efforts, managed care systems need to develop coordinated linkages with them.

Because of federal regulations governing Medicaid or state design parameters, certain subpopulations of children with special needs will become disenrolled from managed care as they move from one placement to another. For example, youth involved in the juvenile justice system can be enrolled in managed care if they are in a community setting but must be disenrolled if they enter a state detention facility. Many state plans cover children involved in the child welfare system but may disenroll them if they are in state custody or enter certain treatment facilities, such as residential treatment. Continuity of care may be threatened by these unique disenrollment issues. State purchasers need to consider the impact of disenrollment parameters on children with special needs through a somewhat different lens than for the larger population.

Clinical Decision Making Protocol Issues

Another issue facing purchasers of managed care for children with special needs is the need for, and general lack of, customized clinical decision making tools, including screening and assessment instruments, level of care protocols, parameters around utilization, and the like. There are a variety of reasons for this. In some arenas, for example, children’s mental health, efficacy-based treatment protocols are poorly developed in the field in

general so it is not surprising to find a scarcity of relevant clinical decision making tools within publicly financed managed care. Clinical protocols historically used in commercial managed care tend to have little relevance for children with serious and complex disorders who are involved with multiple public systems. The conclusive treatment guidelines found in the industry are not readily applicable to children with special needs who fall outside of “usual and customary standards of care”. The public sector has begun relatively recently to enroll children involved in child welfare and juvenile justice systems in managed care arrangements so protocols relevant to these populations within managed care also are in early developmental stages.

On the other hand, state designers and purchasers of managed care are beginning to take steps to develop clinical decision making protocols with greater relevance for “high utilizing populations” in managed care, including children with special needs. Most states, for example, have broadened medical necessity criteria to allow for consideration of psychosocial and environmental considerations, in addition to purely “medical” criteria. States, particularly those with carve outs, are developing level of care criteria specific to various populations of children with special needs. Also, there is a growing body of knowledge developing in the system of care movement with respect to clinical decision making criteria and protocols for children with special needs that can help to inform state purchasers of managed care.

Care Coordination Issues

Children with special needs require a level of care coordination that, historically, has eluded fee-for-service systems and which, not surprisingly, poses major challenges within managed care arrangements as well. As noted earlier, children with special needs tend to be involved with multiple providers and systems, and those involvements change, sometimes frequently, over time. The process of coordinating care takes time and, historically, has not been reimbursed, certainly not by commercial managed care. Yet, managed care in the public sector has far greater potential than fee-for-service arrangements to lodge accountability for care coordination—within medical homes, lead provider agencies, care management entities

and the like. It is a characteristic of systems of care to create this type of accountable entity.

If one is taking a population focus and thus considering the total delivery system, care coordination has to be approached as both an “intra” and “inter” issue in managed care—that is, state purchasers need to be concerned about both the coordination of care provided within the managed care system and coordination between the managed care system and other child-serving systems. Systems of care tend to utilize “child and family care planning teams” to hold multiple providers and systems accountable, as well as a designated care manager to ensure that families can utilize services and supports effectively and efficiently across providers and systems. These are strategies that can be incorporated into larger managed care initiatives as well, or, alternatively, organized pathways developed between the managed care initiative and systems of care that provide customized care coordination.

Cross-System Trouble Shooting Mechanisms

Related to the issue of care coordination at the service delivery level is that of interagency coordination at the larger systems level, that is, at the state (and county) policy and administrative levels. When children with special needs are enrolled in Medicaid managed care, the other systems that share responsibility for their care—e.g. child welfare, education, juvenile justice, mental retardation/developmental disabilities, maternal and child health programs, etc.—become, in effect, “consumers” of managed care, that is, they are using the managed care system to provide for some (or all) of the treatment needs of the children they also serve. In addition, by enrolling children with special needs, the larger managed care system assumes shared liability for these children. Numerous policy and operational issues need to be negotiated among these multiple systems, and re-negotiated over time as implementation issues arise. Increasingly, states are creating cross-system policy making and trouble shooting mechanisms to support coordinated pathways to care at the service level and resolve issues such as liability at the policy level.

Network Adequacy Issues

The network that is developed for the larger population is unlikely to meet the diverse requirements of children with special needs and so, once again, customization is needed. For example, children involved in child welfare need access to specialty providers in sexual abuse treatment, among others; children with special physical health care needs require access to a range of pediatric specialists, and they, as well as children with serious behavioral health disorders, need access to a range of home and community based service providers.

Recognizing the need for customization is one thing; knowing *how* to customize is quite another. There are few algorithms that clarify “how much of what is needed”, that is, that define adequacy within a network serving children with special needs (and, of course, the more subpopulations of children with special needs that are encompassed, the more complicated the challenge). On the other hand, there are systems of care serving various subpopulations of children with special needs that are amassing operational experience with network development that may offer parameters for network adequacy.

Even with a better sense of network parameters, state and county purchasers of managed care for children with special needs must still contend with the historic challenge of insufficient service capacity. There simply is not adequate service capacity available to the public sector among certain specialties, for example, child psychiatrists in many parts of the country, or among certain treatment modalities, particularly home and community-based alternatives to institutional care, or among racial, ethnic and linguistically diverse providers. This is particularly, though not solely, an issue in rural and inner city communities. Re-direction of dollars from inpatient, institutional and residential settings to home and community-based alternatives is a key strategy for augmenting needed service capacity within existing fiscal constraints, and it is a strategy that can be enhanced by managed care through its capacity to incentivize network parameters.

The issue of insufficient service capacity is one that may be aggravated or alleviated by managed care. Inadequate rates paid by Medicaid, increased administrative burdens imposed on providers by managed care, and onerous utilization management procedures all can aggravate the supply problem. On the other hand, some state purchasers have used managed care as an opportunity to broaden Medicaid provider panels and to increase rates through risk-based contracting arrangements, including case rates and performance incentives. In addition, some managed care systems create a favorable trade-off for providers between enhanced flexibility and greater accountability that encourages them to join networks.

Network adequacy in managed care for children with special needs also must concern itself with the availability of informal and natural supports for families and the interface between these and more formal, clinical services. Again, this requires a degree of customization over and above what may be required for the general population. Systems of care are developing experience with linking treatment services and informal supports in a coordinated, holistic services approach that is instructive for large-scale public sector managed care initiatives focusing on a total population of children, including those with special needs.

Accountability System Challenges

The products available through the commercial managed care industry that pertain to accountability systems, such as quality and outcome measurement and even utilization management, are not particularly relevant to children with special needs, though adaptation is possible. Industry accountability products have developed from experience serving, primarily, commercially insured, acute care populations. Quality, cost and outcome measures, and utilization parameters pertaining to care for children with special needs may look very different from those developed for a commercially insured, acute care population. For example, safety (child safety and community safety) is an important measure to track for the child welfare and juvenile justice populations, and one that is not likely to be incorporated into industry standards. The managed care system may not have lead responsibility for ensuring the safety of these children or of the community, but it can be

argued that it shares responsibility with other publicly financed agencies when it enrolls these populations. Thus, “safety” becomes a measure that must be incorporated into accountability systems in managed care initiatives serving children with special needs, and safety as a measure requires customization both beyond what is required by the larger population, as well as in its own right to be responsive to the particular mandates of the child welfare and juvenile justice systems, respectively.

The public child-serving systems that historically have served children with special needs only recently have begun to develop quality and outcome measurement systems; most are in early developmental stages, and most do not have experience with utilization management. Thus, publicly financed managed care faces the challenge of adapting or developing new accountability systems. This is another area where the experience of systems of care may be instructive.

Cost measurement systems also require customization, especially if a state is interested in knowing the total cost of health and behavioral health care for children with special needs. As noted earlier, it is rare for the managed care system to control all of the dollars that support health and behavioral health care delivery for children with special needs. Assuming interest in tracking total cost (and cost shifting), states face the challenge of coordinating cost measurement across systems. Again, some systems of care have begun to develop cost data for certain subpopulations of children with special needs that begin to approximate a total cost of treatment picture.

State purchasers have been especially reliant on commercial managed care companies for utilization management expertise. However, this experience derives primarily from managing commercially insured populations. Customization is needed for managing utilization by children with special needs who are involved with multiple public systems. By definition, these children are “high utilizers”, but within their ranks are also outliers. Because, as has been mentioned, the state of the art and existing data regarding expected levels of utilization are poorly developed, developing utilization parameters is an ongoing challenge. Because they operate across systems, systems of care, where they exist, may have a clearer sense of

utilization parameters than any one agency serving children with special needs at the state level.

Monitoring satisfaction with services on the part of families and youth with special needs also requires customization. A number of state purchasers have implemented targeted strategies, such as focus groups or contracts with family organizations, to measure satisfaction.

Issues Related to Partnering with Families and Cultural Competence

Systems of care recognize the critical role played by families as the primary care givers for their children on an ongoing basis and incorporate strategies that respect and build on the capacity of families. This makes sense from both a quality and cost of care standpoint. Development of meaningful partnerships with families at service and systems levels takes time and may require changes in attitudes and skills on the part of both families and providers. The kind of enduring and active partnerships needed with families who have children with special needs entails customized approaches beyond what is needed for the general population of children with brief, acute care needs.

A very basic, critical support for families of children with special needs is access to reliable information. Some states are contracting with family organizations to develop family information centers tied to managed care systems. Another resource for families is access to peer support, that is, support from families who have children with special needs and share similar experiences. Again, a number of states are contracting with family organizations to develop peer support networks accessible through managed care systems. Both systems of care and managed care systems are employing family members as care managers and family advocates. These are just some of the examples of customized approaches state purchasers are taking to partner with families, recognizing, utilizing, and building the capacity of families as primary care givers.

Cultural competence is an issue in public sector managed care in general, but it takes on additional significance with respect to children with special needs.

In the first instance, children of racial and ethnic minority status are over represented in the population of children with special needs so that culturally relevant service approaches and outreach are especially important. Racial and ethnic minority children with special needs also tend to be over represented in “deep end”, more restrictive levels of care and under represented in home and community based services. As noted earlier, there is a shortage of racial and ethnic minority providers, particularly within specialty areas. Typical purchasing specifications pertaining to cultural competence requirements for provider networks, for outreach efforts and the like may not be sufficiently customized to encompass children with special needs.

CREATING A FIT BETWEEN SYSTEMS OF CARE AND MANAGED CARE

The question raised by today’s universe of public sector managed care and systems of care initiatives is not whether managed care can be applied to systems of care. That is being done already in system of care demonstrations around the country where managed care technologies, such as case rate financing, organized provider networks, care authorization, utilization management and outcomes monitoring, are being employed. Rather, the question is whether systems of care and large-scale public sector managed care reforms can be integrated, or at least linked, in a way that, from the standpoint of families who have children with special needs, the total delivery system becomes more seamless.

Theoretically, there is a great deal of compatibility between large-scale managed care and systems of care. To illustrate, the chart below depicts the goals of “4th generation” managed care as articulated by the commercial managed care industry. The edits that have been made in italics suggest the very slight tinkering that has to be done to make these goals virtually synonymous with those of systems of care.

New Generation of Managed Care

- Integrates payer, manager and provider ^ *and consumer* of care into an integrated delivery system
- Focuses on a delivery system that provides (treatment) ^ *services and supports* for a defined *children and families* population of (patients) ^ in a defined geographic area
- Provides continuity of care over a full continuum of care through the *period a child and family needs services* entire (episode of the patient's illness) ^
- Has a results orientation that measures not only the process of care, *consumers* but the satisfaction of (patients) ^ *services and supports* and the outcome of the ^ (treatment) provided

Adapted from MEDCO Behavioral Health Care Corporation, 1994

Managed care in the public sector, of course, is not in its 4th generation, but, rather 2nd, maybe heading for 3rd. Conceptually, however, the “4th generation” concept suggests the potential for fit between large scale managed care and systems of care that are developing valuable experience in integrating care for children with special needs and their families.

COMMONWEALTH OF MASSACHUSETTS: DEFINING THE CHALLENGE OF SERVING YOUTH WITH SED AND DD

Kathleen D. Betts, M.P.H.

Deputy Assistant Secretary

Children, Youth and Families

COORDINATED FAMILY-FOCUSED CARE

A multi-agency program serving eligible MassHealth children and their families living in Brockton, Lawrence, New Bedford, Springfield, and Worcester.

The Program: Coordinated Family-Focused Care (CFFC) is a program that helps to coordinate the care of children and adolescents who are at risk for out-of-home placements because of their serious emotional disturbances. The CFFC program builds on family strengths and available support systems to help children remain and function productively in the community.

Approach: Drawing from the belief that families are the most important resource, CFFC develops integrated community-based treatment plans that meet the specific needs of each child and family. Key features of the program include the individual care plan, which identifies the treatment goals and the services and supports offered by CFFC, and care management services that ensure services are integrated, monitored, and evaluated.

Services: CFFC provides family and children with a range of care management and support services to respond to the multiple needs identified by families, such as coordination of care, linkages with community supports, after-school programs, crisis response, individual and family therapy, medication management, and in-home and out-of-home respite care.

Eligibility: A child may be eligible if he or she has a serious emotional disturbance that significantly affects functioning at home, school, or the community. The child must also be between the ages of 3 to 18 years old (the child can be up to age 22

if he or she is also receiving special education), be at risk of psychiatric hospitalization or residential care, be a MassHealth member and enrolled or eligible to be enrolled at the Massachusetts Behavioral Health Partnership, and live in Brockton, Lawrence, New Bedford, Springfield, or Worcester. Other eligibility criteria apply.

Outcomes: Outcomes for youth participating in CFFC will be measured by the level of functioning in the community, hospitalization rates, use of residential placements, school attendance and performance, juvenile justice involvement and family, youth and state agency satisfaction.

Oversight: The CFFC Steering Committee is comprised of the Division of Medical Assistance, the Department of Mental Health, the Department of Social Services, the Department of Youth Services, the Department of Education, the Executive Office of Health and Human Services, the Massachusetts Behavioral Health Partnership, and the Parent/Professional Advocacy League.

Contact: **Brockton**
Brockton Area Multi-Services, Inc.
629 Centre St
Brockton, MA 02301
(508) 587-2579

Lawrence
Children's Friend and Family Services
430 Canal St
Lawrence, MA 01840
(978) 682-7289

New Bedford
Child and Family Services of New Bedford
800 Purchase St, 4th fl
New Bedford, MA 02740
(508) 990-0894

Springfield

Behavioral Health Network, Inc.
110 Maple Street
Springfield, MA 01105
(413) 732-7419

Worcester

Worcester Communities of Care
275A Belmont Street
Worcester, MA 01604
(508) 856-5105

To Request More Information

To ask questions or request more information about CFFC, please contact:

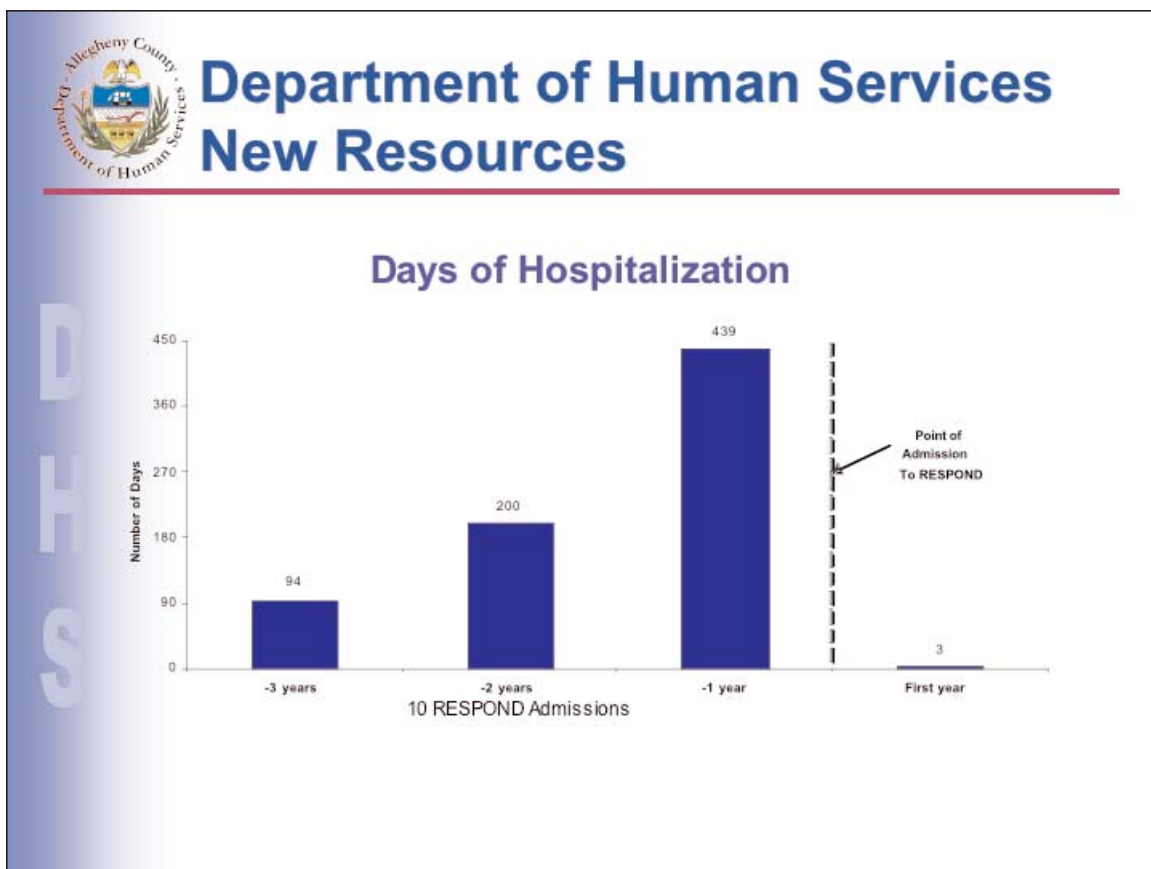
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COMPREHENSIVE AND COORDINATED SYSTEMS OF CARE: ADDRESSING FINANCIAL CHALLENGES

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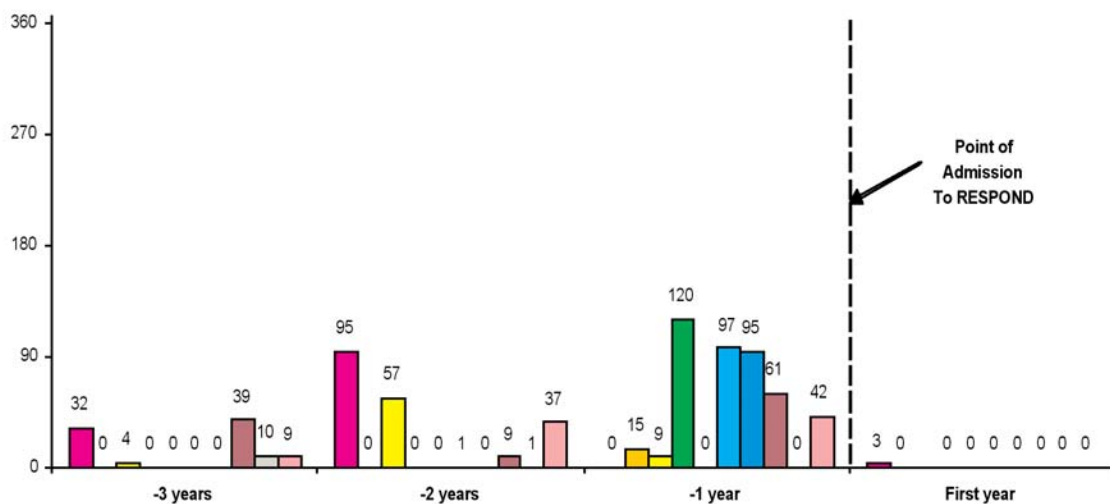


APPENDIX E: SUPPORTING STATE/COUNTY FINANCING DATA

Days of Hospitalization & Incarceration

	Admission	-3 years	-2 years	-1 year	First year
Case #1	5/19/2003	32	95	0	3
Case #2	12/22/2003	0	0	15	0
Case #3	7/21/2003	4	57	9	25
Case #4	8/4/2003	0	0	120	0
Case #5	5/11/2003	0	0	0	0
Case #6	9/16/2003	0	1	97	0
Case #7	4/7/2003	0	0	95	0
Case #8	2/21/2005	39	9	61	0
Case #9	2/15/2005	10	1	0	0
Case #10	6/17/2004	9	37	42	0
Total		94	200	439	28
Total Minus Incarcerations		94	200	439	3

Days of Hospitalization



Respond Client Prior Psychiatric Hospitalizations

Case:	ENTRY TO RESPOND	WPIC ADMISSION DATE	DISCHARGE DATE	# of Days	OTHER SETTINGS
#1	5/19/2003	7/28/2003	7/31/2003	3	10/02 (dates are unknown but was admitted 2 x month)
		8/4/2001	11/7/2001	95	12/02 (dates are unknown)
		5/10/2000	6/20/2000	41	1/03 (dates are unknown)
		4/15/2000	5/9/2000	24	
		3/30/2000	4/14/2000	15	
		3/8/2000	3/23/2000	15	
		2/2/2000	3/3/2000	30	
		1/15/2000	2/1/2000	17	
#2	12/22/200	11/13/2003	11/21/2003	8	
		11/28/2003	12/5/2003	7	
#3	7/21/2003	4/29/2004	5/18/2004	19	
		4/17/2004	4/23/2004	6	
		8/20/2002	8/29/2002	9	11-04-00 to 3/05/01
		3/14/2002	4/12/2002	29	3-18-99 to 3/30/99
		12/2/2001	12/30/2001	28	12/98 to 2/99
		2/1/2000	7/24/2000	174	
		7/20/1999	8/5/1999	16	
		3/31/1999	5/14/1999	44	
		3/20/1992	5/19/1992	60	
#4	8/4/2003			120	3/03 to 8/04/03
#5	5/11/2003	NO KNOWN HOSPITALIZATIONS			
#6	9/16/2003	8/15/2003	9/16/2003	32	
		5/25/2003	6/20/2003	26	
		5/4/2003	5/9/2003	5	
		2/7/2003	3/4/2003	25	
		9/15/2002	9/25/2002	10	

APPENDIX E: SUPPORTING STATE/COUNTY FINANCING DATA

Respond Client Prior Psychiatric Hospitalizations

Case:	ENTRY TO RESPOND	WPIC ADMISSION DATE	DISCHARGE DATE	# of Days	OTHER SETTINGS
#7	4/7/2003	1/11/2003	1/27/2003	16	11/14/00 to 3/27/01 10/00 few days (but specific dates unknown)
		10/17/2003	12/27/2003	71	
		8/4/2002	8/12/2002	8	
		3/24/1999	3/30/1999	6	
#8	2/21/2005	2/3/2002	2/20/2002	17	
		6/17/2002	6/28/2002	11	
		7/17/2002	7/25/2002	8	
		10/1/2002	10/9/2002	8	
		10/11/2002	10/23/2002	12	
		7/8/2003	7/17/2003	9	
		11/22/2004	11/29/2004	7	
		12/22/2004	12/29/2004	7	
		1/5/2005	1/10/2005	5	
		1/10/2005	2/21/2005	42	
#9	2/15/2005	9/18/1998	12/16/1998	89	
		1/28/2002	2/5/2002	8	
		1/18/2003	1/28/2003	10	
		4/17/2003	4/18/2003	1	
#10	6/17/2004	9/25/2001	10/4/2001	9	
		9/27/2002	10/9/2002	12	
		11/22/2002	11/27/2002	5	
		1/21/2003	1/31/2003	10	
		4/8/2003	4/18/2003	10	
		9/10/2003	9/12/2003	2	
		5/4/2004	5/12/2004	8	
		5/14/2004	5/28/2004	14	
		5/29/2004	6/7/2004	9	
		6/8/2004	6/17/2004	9	

APPENDIX F: BIOGRAPHICAL SKETCHES

FACILITATORS/PRESENTERS

HONORABLE MARGARET J. GIANNINI, M.D., F.A.A.P. was appointed October 1, 2002, Director of the Health and Human Service Office on Disability by Secretary Tommy G. Thompson. She serves as advisor to the Secretary on HHS activities relating to disabilities. Prior to becoming Director of the Office on Disability, Dr. Giannini was appointed by President George W. Bush as the Principal Deputy Assistant Secretary for Aging at the Department of Health and Human Services. From 1981-1992, Dr. Giannini was Deputy Assistant Chief Medical Director for Rehabilitation and Prosthetics at the Department of Veterans Affairs, Washington, D.C. There her work focused on technology transfer and assistive technology involving all disabilities. In 1979, President Jimmy Carter appointed Dr. Giannini as the first Director of the National Institute of Handicapped Research, which was confirmed by the Senate in January of 1980. Dr. Giannini, in 1950, was the first to create the largest facility for mentally retarded and the developmentally disabled for all ages and etiologies in the United States and the world, which became the first University Center of Excellence on Developmental Disabilities.

Dr. Giannini is the recipient of many national and international awards from various organizations in recognition of her professional and humanitarian services and achievements. She was saluted by the Association for Pediatric Research; selected “Woman of the Year” for Achievement in Medicine and “Woman-Doer” by President and Mrs. Lyndon B. Johnson; received the Wyeth Medical Achievement Award; the Seal of the Inner London Education Authority for Contributions in the Field of Mental Retardation at the House of Parliament London; and the Governor Hugh Carey Citation for Leadership and Medical Contributions to the State of New York; presented the First Honorary Degree by Mercy College Doctor of Humane Letters; the Meritorious Honor Award in Mental Retardation and awarded the Key to the City of Bologna, Italy; received the Bronze Medal Award by the American Academy of Pediatrics; the National Italian-American Foundation Award for Distinguished Achievements in Science and Medicine; “Recognition Plaque’

from the City of San Francisco; Seton Award from Seton Hall College, Pittsburgh, PA; the First Presidential Award for Design Excellence from President Reagan; the N. Neal Pike Award for Service to the handicapped from Boston University; the Isabelle and Leonard H. Goldenson Award for Technology Application to Cerebral Palsy; President Reagan's Distinguished Service Award, Committee on Employment of the Handicapped; Silver helmet Award by AMVETS; is in the New York Hall of Fame (AHRC, '98); and was honored by the naming of the "Hon. Margaret J. Giannini, M.D. Physical Rehabilitation Pavilion" in 1997 at Westchester Special School, N.Y. First International Leadership Scholars Award by the University of Maryland, Baltimore, Maryland in recognition for "International Programs in Rehabilitation and Disability."

Dr. Giannini has served on numerous national and international boards and chaired more than 61 international conferences on rehabilitation and developmental disabilities in many countries, including Israel, Italy, Spain, China, Russia, Argentina, India, Egypt and others. She also has served for many years as Chair of the Board of Trustees, the American University of Rome, Italy. She has published extensively and lectured nationally and internationally. Dr. Giannini has most recently edited "Behavioral Neurology in the Elderly," December 2001. She is also a Member of the Institute of Medicine of The National Academy of Sciences and Fellow of the American Academy of Pediatrics.

PATRICIA MORRISSEY, PH.D. was appointed by the President in August of 2001, to serve as the Commissioner of the Administration on Developmental Disabilities, Administration for Children and Families U.S. Department of Health and Human Services. She oversees four discretionary grant programs authorized by the Developmental Disabilities Services and Bill of Rights Act of 2000.

Prior to Pat's appointment she was the Senior Associate, Booz-Allen & Hamilton, Worldwide Technology Business, Disability Consulting Services, advise clients on effective and compliant means to provide opportunities for and services to individuals with disabilities.

While in government and working in the private sector, Pat has worked tirelessly for over 30 years to change perceptions, attitudes and living

conditions of the disabled community through changes to national legislation. She served as the senior disability policy advisor for the Senate Committee on Health, Education, Labor and Pensions, and was responsible for legislation on federal disability policies such as The Individuals with Disabilities Education Act Amendments of 1997, The Rehabilitation Act Amendments of 1998, The Education of the Deaf Act Amendments of 1998, The Assistive Technology Act of 1998, The Ticket to Work and Work Incentives Improvement Act of 1999 and the Developmental Disabilities and Bill of Rights Act Amendments of 1999. Pat has written extensively on a variety of disabilities issues including *A Primer for Corporate America on Civil Rights for the Disabled* (1991) and *Employer's Guide to the Americans with Disabilities Act* (1991, supplements in 1992, 1993, and 1994).

She received her A.A. in liberal arts (1964) from Harford Community College, her B.A. in psychology (1966) from Stetson University and her M.Ed. (1971) and Ph.D. (1974) in special education from Pennsylvania State University.

GARY M. BLAU, PH.D. is a Clinical Psychologist and is currently the Chief of the Child, Adolescent and Family Branch of the Center for Mental Health Services. In this role he provides national leadership for children's mental health and is responsible for implementing the Comprehensive Community Mental Health Program, the Circles of Care Program, the National Children's Mental Health Social Marketing Campaign, the National Technical Assistance Programs, and a wide variety of other programs designed to improve the lives of children and families. Through the Director of the Center for Mental Health Services and the SAMHSA Administrator, he is also responsible for translating the President's New Freedom Commission Report for children and families, and for implementing the children's portion of the CMHS Action Plan.

Prior to this, Dr. Blau was the Bureau Chief for the Bureau of Quality Management at the Connecticut Department of Children and Families (DCF). In this capacity Dr. Blau had responsibility for DCF's oversight of child welfare, juvenile justice, substance abuse and mental health service providers, including outpatient psychiatric clinics for children, extended day treatment programs, emergency shelters, group homes and residential treatment centers. Dr. Blau was also responsible for DCF's administrative

case reviews, child fatality investigations, program planning and development, policy and regulation and the DCF Training Academy. Dr. Blau also served as DCF's Director of Mental Health and provided leadership and oversight to Connecticut's mental health service delivery system for children and adolescents.

Dr. Blau was formerly a member of the National Association of State Mental Health Program Director's Division of Children, Youth and Families, and from July 1, 1998 through June 30, 2000 he was the Division's Chairperson. Dr. Blau has received several awards including the prestigious Governor's Service Award, the Phoebe Bennet Award for outstanding contribution to children's mental health in Connecticut, and the Making a Difference Award presented by Connecticut's Federation of Families for Children's Mental Health. He currently holds a clinical faculty appointment at the Yale Child Study Center. Since receiving his Ph.D. from Auburn University (Auburn, Alabama) in 1988, Dr. Blau has worked in children's mental health with a primary emphasis on issues of victimization, child custody, permanency planning and innovative service models. He has held an appointment on the editorial board of the Journal of Primary Prevention, and has numerous publications and presentations in the areas of child custody, primary prevention, managed care and clinical service delivery.

SYBIL K. GOLDMAN, M.S.W., is the Senior Advisor for Children, within the Office of the Administrator and the Office of Policy, Planning and Budget in the Substance Abuse and Mental Health Services Administration (SAMHSA), an Agency within the U.S. Department of Health and Human Services (HHS). Prior to serving in this position, Ms. Goldman was the Director of the National Technical Assistance Center for Children's Mental Health at the Georgetown University Child Development Center, Georgetown University Medical Center Department of Pediatrics where she is an Assistant Professor. Ms. Goldman has over 30 years experience in health, mental health, substance abuse, and human services at the national, state, and local levels involved in policy, administration, research, training, service delivery, and advocacy. She is the author of numerous publications on child health and mental health policy and service delivery. At the Georgetown National Technical Assistance Center for Children's Mental Health she assisted states and communities in building systems of care and improving service delivery for children and adolescents with behavioral

health problems and their families. She has staffed and served on many task forces and coalitions including the President's New Freedom Commission on Mental Health and the Surgeon General's National Action Agenda for Children's Mental Health.

Ms. Goldman received her B.A. degree from Tufts University, M.S.W. from Rutgers University, Post Master's in Health Services Administration from George Washington University, and completed the Senior Managers in Government Program at Harvard University's John F. Kennedy School of Government.

PHYLLIS R. MAGRAB, PH.D., Professor of Pediatrics, has dedicated her career to improving the quality of life of vulnerable children and their families. For the past forty years she has provided service, conducted research, and trained other future professionals in the care of children with chronic illnesses, disabilities and mental health needs and their families. She has been Director of the Center for Child and Human Development Center, a major research and training and public policy program since 1975 and also has been Chief of Pediatric Psychology since 1969. Dr. Magrab has written/edited ten major books as well as written numerous articles and chapters that reflect her personal commitment and philosophy of caring.

She was one of the founders of the field of pediatric psychology and her text, *Psychological Management of Pediatric Problems*, represents one of the firsts works in the field that established its academic presence. She received the Distinguished Contributions Award from the American Psychological Association, Society of Pediatric Psychology for her efforts in 1985.

She has contributed significantly to the field of training clinical psychologists and has served as chairperson of both committees and conferences that have further defined the field. For these contributions, she received the Distinguished Service Award from the Division of Clinical Psychology of the American Psychological Association in 1991. In 1999, she was honored by Georgetown University for her teaching when she received the inaugural Estelle Ramey Medical Women Faculty Award, a tribute to her commitment to sharing knowledge and creating a community of caring professionals.

Over the past two decades she has been actively involved in developing public policy to insure society's commitment to children and youth with special needs. She was one of the pioneers in the field of maternal and child health and children's mental health to establish community-based, family-centered systems of care for children and youth with disabilities, chronic medical conditions and mental health needs. She has consulted with professionals and public health leaders in practically every state in this country around developing policies and implementing systems change towards this goal. She was the recipient of the Surgeon General's Award for Distinguished Service for this work in 1988 and the John C. Mac Queen Award of the Association of Maternal and Child Health in 2002. In the early 1990's she was asked to work with the Ministries of Health in Hungary and Czechoslovakia to apply these concepts to the decentralization of health care that has taken place in Central and Eastern Europe. One of her recent books, *Where Children Live*, is a compendium of effective community solution to serving children and their families, both nationally and internationally.

Currently, Dr. Magrab is actively involved in global issues related to social exclusion. She is working with UNESCO on their agenda of Education For All and with the OECD on policies for serving at-risk children in their communities. She is especially concerned with the social justice issues surrounding global initiatives that relate to children and the human rights agenda.

PANELISTS

PANEL I

GERALDINE TONICH is a parent representative from Family Ties in Westchester County, New York. She is the mother of three sons, ages thirteen, nine and six. For the last year and one-half, she has worked as a Personal Assistant to a child with Asperger's Disorder. She has recently been promoted to the position of Family Ties Resource Specialist, with responsibility for family support activities in two northern Westchester Resource Centers.

MYRA ALFREDS, CSW, is the Director of Children’s Mental Health Services in the Westchester County Department of Community Mental Health. She is also the Project Director and Principal Investigator for the *Westchester Community Network*, a federally funded, nationally recognized, community based system of care for children with serious social, emotional and behavioral difficulties and their families. Network is built on principles and values that promote cross-systems, culturally competent, individualized care that is family and youth driven and supports child and family strengths. The *Westchester Community Network* is known for its community-based Network system, its county-wide family and peer support movements, its use of respite and therapeutic recreation and its specialized services for youth with high risk behaviors, such as sexual reaction/aggression and fire setting. The *Westchester Community Network* has been designated by the federal government as one of three *Team Learning Collaboratives* that welcomes visitors from other communities and states from throughout the country to learn about *System of Care* work. Ms. Alfreds has worked extensively in many different systems, including adult and youth education and employment, social services, youth parole, drug and alcohol prevention and treatment, runaway and homeless youth services, and children’s mental health. She speaks widely on a variety of topics that reflect the innovative work that occurs in Westchester County. Recent topics have included, “Leadership within the System of Care,” Development of Community-based Networks,” “Inter-agency Collaboration for Children with Co-Occurring Mental Health and Developmental Disabilities,” and “The Use of Evidence-based Practices within the System of Care.” She is the recipient of the New York State Department of Social Services “No Time to Lose Award” for Outstanding Community Services for promoting and expanding the Network Model.

CHARLIE BISS, M.S.W. Charlie has been with the Vermont State Department of Developmental and Mental Health Services’ Division of Mental Health for the past 18 years. He has been the Director of the Child, Adolescent and Family Unit for the past 13 years. He has 32 years of Human Services experience as a clinician, local program developer, and a state level implementer of systems of care. This experience has taught him the importance of consumer and family involvement, building local community-based services and supports, and focusing on prevention and early intervention.

CHERYLL BOWERS-STEPHENS, M.D., M.B.A. is the Assistant Secretary for the Office of Mental Health in the Louisiana Department of Health and Hospitals. She is a graduate of Spelman University, with an undergraduate degree in psychology and computer science. She also holds a MBA from the University of New Orleans and an MD from Louisiana State University in New Orleans. Her general psychiatry residency was at the Ochsner Medical Foundation, followed by a child and adolescent fellowship at Tulane University. Her clinical area of expertise is treatment of youth with co-occurring mental illness and developmental disability. She has served for the past ten years in program administration and program development. In this role, she has emphasized the importance of infant mental health, services to at-risk youth ages 0-5 and their families, and collaboration at the community level. She is currently engaged in Project Legacy, an effort to transform mental health for the State of Louisiana.

PANEL II

PEGGY NIKKEL is the Executive Director of UPLIFT, Wyoming's Federation of Families for Children's Mental Health. She is also the parent of a son with emotional and learning disorders. Mrs. Nikkel has worked closely with government officials, researchers and clinicians to improve services for children, particularly to institute early screening and intervention programs. Her advocacy efforts led to the development of Wyoming's Early Start Program in 1998.

She actively participates on a number of state and national initiatives. Her current work in Wyoming is focused on system of care development through the Governor's Mental Health Planning Council and the Governor's Children and Families Initiative Advisory Council. She has partnered with the Georgetown University Center for Child and Human Development on several projects related to early childhood mental health. She also serves as a consultant for other family advocacy organizations across the country through the Substance Abuse and Mental Health Services Administration's Statewide Family Network Program. Additionally, Peggy has served as a conference presenter for a number of state and national conferences and in 2002 she was awarded the *Claiming Children Award* by the National Federation of Families for Children's Mental Health.

STEVE LAFRENIERE, M.S. has worked for the Alabama Department of Mental Health and Mental Retardation (DMH/MR) since 1997 and has served as the Director of Children's Services Office since 2001. This Office was created to administer the specialized Children First Funds that come to the DMH/MR; to provide comprehensive planning for children's services across the three (3) service divisions; and serve as a single point of contact in the department for children's services. Before serving as Director, he held the positions of Coordinator of Child and Adolescent Services and a Resource Specialist within the Mental Illness Division.

Prior to his service at DMH/MR, he was worked at a community mental health center in Montgomery Alabama as a Children's Outpatient therapist and Lead Therapist for an In-Home Intervention Team. The in-home team served children and adolescents with Serious Emotional Disturbances and their families. He is a graduate of Auburn University and received his Master's in Clinical Psychology from Auburn University at Montgomery in 1992, where he taught as a part-time Adjunct Instructor in the Psychology Department until 2001. He lives with his wife and two daughters in Wetumpka Alabama.

KENNETH W. RITCHEY is the Director of the Ohio Department of Mental Retardation and Developmental Disabilities. Governor Bob Taft appointed Kenneth W. Ritchey director of the Ohio Department of Mental Retardation and Developmental Disabilities (MR/DD) on February 11, 1999.

Director Ritchey oversees the human service agency that provides funding, oversight and technical assistance to Ohio's 88 County Boards of MR/DD. More than 68,000 Ohioans receive services and supports through Ohio's MR/DD system.

Director Ritchey received his Bachelor's degree from Shippensburg University (Pennsylvania) and has his Master's degree from the Curry School of Education, University of Virginia. He has a second Master's in Education Administration from the University of Dayton and participated in the Program for Senior Executives in State and Local Government sponsored by the John F. Kennedy School of Government at Harvard University.

Director Ritchey has guided the Department of MR/DD through a number of significant changes and accomplishments. Some of the major initiatives under his leadership include: a complete redesign of Ohio's Medicaid system for people with disabilities; major health and safety initiatives; restructuring of the department's table of organization; expansion of Ohio's Self-Determination project; development of important Interagency Agreements and collaboratives; settlements of long-standing lawsuits; consolidated State developmental services and the implementation of Ohio's MR/DD Vision Paper.

PANEL III

SHEILA A. PIRES, M.P.A. is a founding partner of the Human Service Collaborative of Washington, D.C., a policy and technical assistance group specializing in child and family service systems. Ms. Pires has 30 years of experience in national, state, and local government and non-profit agencies serving children and families at risk. She has held senior staff and management positions in the U.S. House of Representatives, the U.S. Department of Health, Education and Welfare and the Carter White House. She co-chaired the children's mental health and substance abuse committee of President Clinton's Task Force on Health Care Reform, and co-authored the children's issue brief and policy recommendations for President Bush's New Freedom Mental Health Commission. She is a co-Principal Investigator of the only national study analyzing the impact of Medicaid managed care on children with behavioral health disorders and their families and serves as the Senior Consultant to the Children in Managed Care Program at the Center for Health Care Strategies. At the state and local level, Ms. Pires served as Deputy Commissioner of Social Services for the District of Columbia and, prior to that, led a reorganization of the city's mental health system as head of child mental health services. She has consulted with states, counties, cities, neighborhoods, and family organizations and has authored numerous publications on systems change, including *Building Systems of Care: A Primer*. Ms. Pires received her B.A. from Boston University and a Master in Public Administration from Harvard University.

KATHLEEN BETTS, M.P.H. is currently Deputy Assistant Secretary for Children, Youth and Families in the Commonwealth of Massachusetts. Children, Youth and Families oversees the following agencies: child welfare,

juvenile justice, welfare, children's trust fund and refugees and immigrants. Kathy is a graduate of Boston College and has a Master's Degree in Public Health from Boston University. She has over 20 years of experience in program development and analysis in state government. Prior to her recent return to state service, she was the director of child and adolescent services for the Medicaid Mental Health Carve- Out Program.

MARC CHERNA was appointed the Director of the Allegheny County Department of Human Services (DHS) in January 1997. As DHS Director, he is responsible for overseeing the ongoing operations of this Department, which brings under one umbrella, with a shared vision and goals, five programmatic offices: Children, Youth and Families, Mental Retardation/Developmental Disabilities, Community Services, Behavioral Health, and the Area Agency on Aging. The Department operates with a combined budget of \$715 million, approximately 1200 employees, contracts with over 500 service provider agencies, and serves approximately 250,000 county residents a year.

Marc first came to Allegheny County in February 1996 as a result of a national search to take charge of the county's child protective service agency and immediately implemented system-wide changes that have resulted in better permanency outcomes for children. These reforms received national recognition and were showcased by CNN on NewsNight with Aaron Brown.

Marc's innovative practice and leadership abilities have also garnered him prestigious awards by numerous child welfare, humanitarian, and civic organizations such as; the Betty Elmer Outstanding Professional Award from Family Resources; the Urban League's Ronald H. Brown Civic Leadership Award; the Good Government Award from the League of Women Voters. He serves on many boards and committees such as the University of Pittsburgh's School of Social Work's Board of Visitors, the Executive Committee of the National Association of Public Child Welfare Administrators and the Child Welfare League of America's National Advisory Committee on Foster Care, The United Way of Allegheny County and the Three Rivers Workforce Investment Board.

APPENDIX F: BIOGRAPHICAL SKETCHES

Marc began his career in human services as a youth worker over 30 years ago. He has extensive work experience in the field, including four years as the Director of Planning, Allocations and Agency Relations with the United Way of Union County, New Jersey and almost 14 years with the New Jersey Department of Human Services as an Assistant Director with the New Jersey Division of Youth and Family Services in the areas of Policy, Planning and Support and Program Operations and as a Special Assistant to the Deputy Commissioner.

Marc received his B.A. degree from the State University of New York at Binghamton and an M.S.W. from the Hunter College School of Social Work in New York. He has three children and three grandchildren.